

**THE EXPERIENCES OF TRANSPORT SECTOR EMPLOYEES AFTER THEIR  
DISCLOSURE OF LIVING WITH HIV IN THE WORKPLACE**

**by**

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**Dedicated to all those who live with HIV in the workplace**

**Like many, you have experienced things that caused you to judge yourself unworthily. The biggest challenge of your life is to heal the wounds of the past so that you do not continue to bleed.**

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## **ABSTRACT**

### **THE EXPERIENCES OF TRANSPORT SECTOR EMPLOYEES AFTER THEIR DISCLOSURE OF LIVING WITH HIV IN THE WORKPLACE**

**BY**

**LINDA YVONNE PETER**

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Despite the global and local response to the HIV epidemic, the disclosure of HIV status in the workplace is still a problem globally and in South Africa, due to the stigma attached to the disease. However, often, by “going public” about their HIV status, HIV infected people give a face to the disease. This however has not been the case in the workplace due to fear of discrimination and stigma (Lutaaya, 1999; Van der Borght, van ,Janseens, der Loeff, Kajemba, Rijckborst, Lange & de Wet, 2009:676).

It has been discovered that HIV and AIDS are not only medical problems but a psycho-social issue as well. Adding to the problem of HIV status disclosure in South Africa prior to 2010, HIV and AIDS were met with denial and a lack of political will to take action and thus adding to the reluctance in HIV status disclosure. The goal of the study was to explore the experiences of HIV positive employees in the transport sector after they have disclosed their HIV status in the workplace. A qualitative phenomenological approach was appropriate for this study using in-depth interviews. And as such one question that was put forward to all participants was: How would you describe your daily living with HIV after you have disclosed your HIV status in the workplace?

Fifteen participants from Organisation Alpha formed a sample for this study. Some conclusions based on the findings were that:

Participants' experiences varied from one participant to the other. There were participants who experienced support in the workplace while others experienced isolation and rejection. One issue that stood out was the experience of stigma in the workplace. The experiences felt by the participants were mostly attributed to lack of HIV knowledge in the workplace which needs to be addressed by the application of various strategies and action programmes. The study was concluded with relevant recommendations to the transport sector.

**Key words**

Employee

Workplace

Disclosure

HIV

AIDS

## **OPSOMMING**

### **DIE ERVARINGS VAN WERKNEMERS IN DIE VERVOER SEKTOR NA DIE BEKENDMAKING VAN HUL HIV STATUS IN DIE WERKPLEK**

**DEUR**

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Ondanks die globale en plaaslike reaksie tot die HIV epidemie, bly die bekendmaking van HIV status in die werkplek steeds 'n probleem op globale vlak sowel as in Suid Afrika, weens die stigma wat aan die siekte gekoppel word. Dikwels, deur hul HIV status in die openbaar bekend te maak, skep die HIV geïnfekteerde persoon 'n beeld van die siekte. Dit is egter nie die geval in die werkplek nie, weens die vrees vir diskriminasie en stigma (Lutaaya, 1999; Van der Borgh, van der Loeff, Rijckborst & de Wet, 2009:676).

Dit is bevind dat HIV en VIGS nie uitsluitlik 'n mediese probleem is nie, maar dat dit ook 'n psigo-sosiale kwessie is. 'n Bydraende faktor tot die probleem van HIV status bekendmaking/onthulling in Suid Afrika voor 2010, is dat HIV en VIGS ook gekenmerk word deur ontkenning en 'n tekort aan politieke wilskrag om aksie te neem, dus verder bydraend tot die onwilligheid om HIV status bekend te maak/te onthul.

Die doel van hierdie studie was om die ervarings van HIV positiewe werknemers in die vervoer sektor te ondersoek, nadat hulle hul HIV status in die werkplek bekend gemaak het. 'n Kwalitatiewe fenomenologiese benadering was gepas vir hierdie studie. Die in-diepte onderhoud is as data insamelingsmetode aangewend. Gevolglik is een van die

vrae wat aan alle deelnemers gestel was as volg: Hoe sal jy jou daaglikse lewe met HIV beskryf nadat jy jou HIV status in die werkplek onthul het?

Vyftien deelnemers van Organisasie Alpha het as steekproef in hierdie studie gedien. Van die gevolgtrekkings wat op die bevindinge van die studie gebaseer is, is as volg:

Deelnemers se ervarings wissel van een na die ander. Daar was deelnemers wie ondersteuning in die werkplek ervaar het, terwyl andere isolasie en verwerping ondervind het. Een opvallende kwessie was die ervaring van stigma in die werkplek. Die ervarings van die deelnemers kon meestal toegeskryf word aan 'n gebrek aan HIV kennis in die werkplek. Dit kan aangespreek word deur die aanwending van verskeie strategieë en aksie programme. Hierdie studie was afgesluit met relevante aanbevelings vir die vervoer sektor.

### **Sleutelwoorde**

- Werknemer
- Werkplek
- Bekendmaking
- HIV
- Vigs

## Table of Contents

Dedication	ii
Acknowledgements	iii
Abstract	iv
Opsomming	vi
<b>CHAPTER ONE: GENERAL BACKGROUND INFORMATION ON THE RESEARCH STUDY</b>	
<b>1.1 Introduction</b>	<b>1</b>
<b>1.2 Research Problem</b>	<b>3</b>
<b>1.3 Goal and objectives of the study</b>	<b>6</b>
1.3.1 Goal of the study	6
1.3.2 Objectives of the study	6
<b>1.4 Research question</b>	<b>6</b>
<b>1.5 Research design and methodology</b>	<b>6</b>
<b>1.6 Feasibility of the study</b>	<b>8</b>
<b>1.7 Ethical Aspects</b>	<b>9</b>
1.7.1 Informed consent from participants	9
1.7.2 Confidentiality	10
1.7.3 Deception	11



1.7.4. Action and competence of the researcher	11
1.7.5 Debriefing of participants	11
1.7.6 Release or publication of the findings	12
<b>1.8 Limitations of the study</b>	<b>12</b>
<b>1.9 Definition of key concepts</b>	<b>12</b>
1.9.1 HIV	13
1.9.2 AIDS	13
1.9.3 Experience	14
1.9.4 Disclosure	14
1.9.5 Employee	14
1.9.6 Transport sector	15
<b>1.10 Division of the research report</b>	<b>15</b>
<b>CHAPTER TWO: HIV IN THE WORKPLACE WITH ITS SPECIFIC EMPHASIS ON HIVS TATUS DISCLOSURE</b>	
<b>2.1 Introduction</b>	<b>17</b>
<b>2.2 Definition of HIV and its progression to AIDS</b>	<b>19</b>
2.2.1 Human Immunodeficiency Virus (HIV)	19
2.2.2 Acquired Immune Deficiency Syndrome (AIDS)	20
<b>2.3 The prevalence of HIV and AIDS</b>	<b>21</b>

2.3.1 Globally	21
2.3.2 Sub-Saharan Africa	22
2.3.3 South Africa	24
2.3.4. Transport Sector in South Africa	25
<b>2.4 Risk Factors associated with the spread of HIV</b>	<b>27</b>
2.4.1 Culture and Social Norms	27
2.4.2 Stigma	29
2.4.3 HIV and Human Rights	30
2.4.4. Poverty	31
2.4.5 Labour related migration	33
2.4.6 Gender-based violence	33
<b>2.5 Impact of HIV on the individual</b>	<b>34</b>
2.5.1 Physical impact	35
2.5.2 Psycho-social impact	35
2.5.3 Financial impact	37
<b>2.6 The impact of HIV in the workplace</b>	<b>37</b>
2.6.1 Absenteeism	38
2.6.2 Financial impact on the workplace	38
<b>2.7 The phenomenon of HIV status disclosure</b>	<b>43</b>

2.7.1 Categories of HIV status disclosure	43
2.7.1.1 Voluntary Disclosure	44
2.7.1.2 Disclosure without consent	45
2.7.2 Factors that influence the decision to disclose HIV status	46
2.7.3 The consequences of HIV disclosure	46
2.7.3.1 Negative consequences of disclosure	46
2.7.3.2 Positive consequences of disclosure	47
2.7.4 HIV status disclosure in the workplace	48
<b>2.8 Summary</b>	<b>49</b>
<b>CHAPTER THREE: RESEARCH METHODOLOGY, EMPIRICAL RESEARCH FINDINGS AND INTERPRETATION</b>	
<b>3.1 Introduction</b>	<b>50</b>
<b>3.2 Research methodology</b>	<b>51</b>
3.2.1 Research approach	51
3.2.2 Type of research	51
3.2.3 Research design and methods	52
3.2.3.1. Research design	52
3.2.3.2 Population, sample and sampling method	52
3.2.3.3 Data collection method	53

3.2.3.4 Data analysis	54
<b>3.3 Trustworthiness of the research findings</b>	<b>55</b>
<b>3.4 Empirical research findings</b>	<b>56</b>
3.4.1. Section 1: Biographical profile of participants	57
3.4.1.1 Gender	57
3.4.1.2 Age of the participants	58
3.4.1.3 The marital status of the participants	58
3.4.1.4. Racial distribution of participants	59
3.4.1.5 Home language of the participants	60
3.4.1.6 Highest level of education successfully completed by participants	61
3.4.1.7 Occupational levels of participants	62
3.4.1.8 Involvement of participants in antiretroviral treatment (ARV)	63
3.4.1.9 People to whom participants disclosed their HIV status in the workplace	64
3.4.1.10 The period since the participants disclosed their status	65
3.4.2 Section 2: Qualitative information according to themes and sub-themes	66
3.4.2.1 Theme 1: Support systems in the workplace	68
3.4.2.2 Theme 2: Experiences of stigmatisation in the workplace	73

3.4.2.3 Theme 3: Level of HIV knowledge in the workplace	74
3.4.2.4 Theme 4: Reasons for disclosure of HIV status in the workplace	77
3.4.2.5 Theme 5: Benefits after HIV disclosure in the workplace	79
3.4.2.6 Theme 6: Emotional experience after HIV disclosure	80
3.4.2.7 Theme 7: Challenges of being on ARV treatment after HIV disclosure in the workplace	83
<b>3.5 Summary</b>	<b>86</b>
<b>CHAPTER FOUR: CONCLUSIONS AND RECOMMENDATIONS</b>	
<b>4.1 Introduction</b>	<b>88</b>
<b>4.2 Conclusions</b>	<b>89</b>
<b>4.3 Recommendations</b>	<b>91</b>
4.3.1 Recommendations with regard to HIV and AIDS policy	91
4.3.2 Recommendations with regard to HIV and AIDS knowledge capacity building programme for managers and supervisors.	91
4.3.3 Recommendations with regard to integrating HIV and AIDS management in the workplace to management Key Performance Indicators (KPI)	91
4.3.4 Recommendations with regard to support	92

4.3.5 Recommendations with regard to therapeutic programmes	92
4.3.6 Recommendations with regard to further research	92
<b>4.4 Achievement of the goal and objectives of the study</b>	<b>93</b>
<b>4.5 Summary</b>	<b>94</b>
<b>List of References</b>	<b>96</b>
<b>List of Tables</b>	
Table 2.1 Sub-Saharan summary of HIV/AIDS Epidemic 2001 and 2009	23
Table 2.2 South African provincial HIV Prevalence	25
Table 3.1 Summary of the identified themes and sub-themes	67
Table 4.1 Summary of achievement of objectives	93
<b>List of Figures</b>	
Figure 2.1 Impact of HIV and AIDS in the workplace	41
Figure 3.1 Age distribution of participants	58
Figure 3.2 Marital status of participants	59
Figure 3.3 Racial distribution of participants	60
Figure 3.4 Home language distribution of participants	61
Figure 3.5 Highest level of education successfully completed by participants	62
Figure 3.6 Distribution by occupational levels of the participants	63
Figure 3.7 Participants taking antiretroviral treatment (ARV)	64

Figure 3.8 People to whom participants disclose their HIV status in the workplace 65

Figure 3.9 Period after disclosure of HIV status 66

### **List of Appendices**

Annexure A: Informed consent form

Annexure B: Editorial letter

Annexure C: Semi-structured interview schedule

Annexure D: Letter of Ethical Clearance

## CHAPTER ONE

### GENERAL BACKGROUND INFORMATION ON THE RESEARCH STUDY

#### 1.1 Introduction

United Nations on AIDS (2000) observed that when Acquired Immune Deficiency Syndrome (referred to as AIDS) emerged, at that stage three decades ago, few people could predict how the epidemic would evolve, and fewer people still could describe with certainty the best ways of combating it.

As the world enters the third decade of the AIDS epidemic, the rate of infection globally appears to have stabilised. According to the United Nations on HIV/AIDS (2010:16), the annual number of new HIV infections has been gradually declining since the late 1990s when the epidemic reached its peak. It is stated that in 2009 there were an estimated 2.6 million people who became newly infected and this was about 19% lower than the 3.1 million people who were newly infected with HIV in 1999 (United Nations on HIV/AIDS, 2010:16).

In Sub-Saharan Africa, United Nations on HIV/AIDS (2010:16) highlighted that the HIV incidence fell by more than 25% between 2001 and 2009. However, an estimated 1.8 million people were newly HIV infected in 2009. According to the United Nations on HIV/AIDS (2010:16) these improving trends reflect a number of factors, including the impact of HIV prevention efforts and the natural course of HIV epidemics.

South Africa has experienced the most devastating effects of HIV in the world with an estimated 19% of its labour force living with HIV (ILO, 2006:3). Several authors agree that socio-cultural and economic factors contribute to the spread of the virus despite the global response (Cameron, 1993:3; Jackson, 2002:8). The researcher agrees with the above authors' view that socio-economic circumstances and culture are some of the factors that contribute to the spread of HIV, and above all both denial and stigma contribute to non-disclosure of HIV status.



HIV and AIDS are described as life-threatening, progressive medical conditions with psycho-socio-economic impact, not only to the individual but to the family, workplace and the community (Cameron, 1993; Levin, 2005). According to Jackson (2002:294), the effects of HIV in the workplace can be looked at from the employer's and employee's needs, although in some areas their needs overlap while in other areas they diverge.

Employees need improved health care, sick leave benefits, death payouts and pension benefits, while on the other hand employers are facing escalating costs and limited expenditure and still have to sustain productivity. It is therefore in the best interest of both employees and employers to respond effectively to HIV prevention, support and care strategies. This will increase the possibility that employees who are HIV infected are kept healthy and productive for a long period. The South African Business Coalition on HIV and AIDS (2006) asserts that in South Africa there should be a general agreement by business to disclose the potential impact of HIV and AIDS on productivity to enable companies to respond effectively to the scourge. For this to materialise, the organisations and the government should be ready to deal with personal HIV status disclosure in the workplace by eliminating stigma.

The transport sector, including rail, road, air freight, airlines, transport agencies and ports, is one of the largest sectors in South Africa with a high mobility amongst its workers. Due to the nature of their work, transport sector workers have a high risk of HIV infection. This is confirmed by a study conducted by van Aardt (2008:15) who mentioned that more than 50% of the transport sector employees are living with HIV. This is also confirmed in the manual for Transport Workers Taking Action on HIV AIDS [sa], which states that all transport organisations in South Africa are affected by HIV. In this study the researcher wanted to explore specifically the experiences of HIV infected employees within the transport sector after they have disclosed their status in the organisation of their employment. Therefore, due to the sensitivity of the study and to protect the identity of both the individuals and the organisation the organisation will be named Alpha for anonymity in this study, because of the core business and the public image of the organisation.

## 1.2 Research Problem

Despite the global and local response to the HIV epidemic, the disclosure of HIV status in the workplace is still a problem globally and in South Africa, due to the stigma attached to the disease. In most cases, greater involvement of people living with HIV has been strongly promoted by individuals who are living with or affected by HIV and AIDS. They argue that by “going public” about their HIV status, the HIV infected people give a face to the disease. This however has not been the case in the workplace due to fear of discrimination and stigma (Lutaaya, 1999; Van der Borght, Janssens, van der Loeff, Kajemba, Rijckborst Lange & de Wet, 2009:676).

It is evident from the literature that HIV and AIDS is a dynamic and complex phenomenon with serious economic impact on companies. Adding to the problem of HIV status disclosure in South Africa prior to 2010, HIV and AIDS were met with denial and a lack of political will to take action, thus adding to the reluctance in HIV status disclosure (Jackson, 2002:8, ILO, 2006:3). The individuals who live openly with their status are faced with challenges of negative response from their families, communities and workplaces. For instance, in the early 90s the court ruled against South African Airways for denying employment to an individual who disclosed his HIV status to the organisation (Grogan, 2003:259). This is confirmed by James (2006:24) in another court battle where the court ruled against a school that denied admission to a child who was living with HIV.

Furthermore, there is evidence which indicates that most studies have focused on barriers of HIV status disclosure in general. For instance, Nzioka (1996:162) associates the problems of HIV status disclosure in Kenya with limited privacy and confidentiality in overcrowded public health institutions and the low doctor/patient ratio which made it difficult for individuals who tested HIV positive to disclose their HIV status in public health facilities. The author further argues that inadequate medical facilities and high literacy levels of professional people are some barriers to easy HIV status disclosure. Beltran, Ostrow and Joseph [sa] argue that HIV status disclosure is related to a high

level of mental distress and denial-fatalism, a lack of coping strategies and the low level of social support.

On the other hand, Parsons, Schrimshaw, Bimbi, Wolitski, Gomez and Halkitis [sa] postulate that some individuals, particularly those with high risk behaviours, lack strategies to deal with HIV status disclosure. The authors argue that educated people who are diagnosed with HIV sero-positive develop strategies to cover up for HIV and prefer to relate to the affluent diseases such as Diabetes Mellitus, Pulmonary Tuberculosis and Pneumonia instead of HIV infection. It is confirmed by Van der Borgh, Janssen, van der Loeff, Kajemba, Rijckborst, Lange and de Wet (2009:676) that some reasons for HIV status disclosure are associated with the nature of the relationship with the disclosure target.

HIV status disclosure has not been evident in the workplace due to fear of discrimination and stigma. The transport sector, as one of the largest sectors in South Africa with high mobility amongst its workers, is no exception. Van Aardt (2008:15) mentions that more than 50% of transport sector employees live with HIV. Alpha, an organisation in the transport sector, seems to be no different from the other organisations with regard to the impact of HIV.

The researcher has observed that employees living with HIV in Alpha are subjected to a certain form of discrimination, whether directly or indirectly, after they have disclosed their HIV status to their line management. There have been incidents that occurred in the past where employees living with HIV seem to have been humiliated and indirectly discriminated against, and even where working conditions became unbearable for them after they disclosed their status in the workplace, leading them to leave employment.

Experts Maigurira (2007) and Mabonga (2007) confirmed this observation by stating that a number of individuals who have disclosed their HIV status in the workplace have been subjected to discrimination, traumatised and sidelined in work-related issues. These experts further state that some individuals disclosed their HIV status in the

workplace thinking that they would be accommodated, but they were met with hostility instead.

Due to advancement in medical services and science, people infected with HIV continue to live longer, healthier and more productive lives. Therefore, effective management of HIV and AIDS in the workplace is becoming crucial. Effective, supportive, compassionate and ethical HIV management in the workplace requires knowledge of information from employees who are infected with HIV as well as other domains. This cannot be possible for instance, if the organisation is not aware of the number of employees who disclose their HIV status in the workplace. Furthermore, the literature on HIV and AIDS in the workplace seems to focus more on the impact of HIV and AIDS in the workplace, prevention strategies, human rights issues and the prevalence rates. There seems to be less focus on the phenomenon of personal experiences of living with HIV after disclosure in the workplace (Forsyth, Vandormael, Kershaw & Grobbelaar, 2008:74).

The researcher has therefore identified a gap of lack of information regarding HIV infected persons' own experiences in the workplace after HIV status disclosure. Thus, due to lack of knowledge with regards to HIV related disclosure in the workplace, focus of this study will be on an exploration of HIV infected employees' personal experiences of living with HIV in the workplace after they have disclosed their status. Such an exploration will assist in understanding the daily experiences of employees who are HIV infected after they have disclosed their HIV status in the workplace. Thus promoting effective legal, ethical and compassionate HIV and AIDS management in the workplace, assisting employers to accommodate and create a conducive environment for the employees who are living with HIV to remain as healthy and productive as they can be. Effective management of HIV and AIDS in the workplace will not only promote meaningful employment for employees living with HIV, but will be a benefit to employers due to increased productivity and fewer lawsuits related to violation of human rights.

### **1.3 Goal and objectives of the study**

#### **1.3.1 Goal of the study**

The goal of this study is to explore the experiences of HIV positive employees in the transport sector after they have disclosed their HIV status in the workplace.

#### **1.3.2 Objectives of the study**

In order to obtain the goal of the study the following objectives were formulated:

- To theoretically conceptualise HIV as a phenomenon with specific emphasis on HIV disclosure in the workplace;
- to explore the experiences of HIV positive employees in the transport sector after they have disclosed their HIV status in the workplace; and
- to draw conclusions, based on the research findings, and formulate recommendations to address HIV disclosure problems in the workplace.

### **1.4 Research question**

Against this background the following research question was formulated in order to guide the study:

What are the experiences of HIV positive transport sector employees after they have disclosed their HIV status in the workplace?

### **1.5 Research design and methodology**

In order to understand the phenomenon of HIV and AIDS disclosure and specifically the experiences of people living with HIV after they have disclosed their status in the workplace, a qualitative study was deemed the most appropriate approach for this study. As outlined in literature by Bless and Higson-Smith (2000:38) as well as Fouché

and Delport (2011:65), a qualitative research approach is used when a researcher seeks to understand the feelings and experiences of participants as they perceive them and how they view their world.

Furthermore, the most applicable type of research for this study was applied research, because applied research has a strong emphasis on application and solving problems in practice (Fouché & De Vos, 2011:95) as is the case here where HIV disclosure is a problem in practice.

The researcher was of the opinion that employees living with HIV and who have disclosed their HIV status in the workplace are the only people who can really describe their experiences after disclosure. Thus the phenomenological research design was the most appropriate design. The phenomenological design is often described as the design in which both the researcher and the participant work together to “arrive at the heart of the matter” (Leedy & Ormrod, 2005:139). Adding to this, Creswell (in Fouché & Schurink, 2011:16) describes phenomenological design as the “meaning of the lived experiences of a phenomenon by individuals”.

In this study the universe was all the transport sector employees living with HIV and AIDS who have disclosed their HIV status in the workplace. Strydom (2005:151) defines the universe as all subjects who possess the attributes in which the researcher is interested, while Saunders, Lewis and Thornhill (2003:151) describes the population as a set of cases from which a sample is taken.

In this study the population was all the transport sector employees who are living with HIV in organisation Alpha and who have disclosed their status in the workplace. In total the population in this study consisted of 85 employees within the six branches of organisation Alpha who are living with HIV and have disclosed their HIV status in the workplace by the time the researcher collected her data. By using a combination of stratified and systematic sampling, three participants from each branch of the six branches of organisation Alpha were selected to form part of the sample. Thus, altogether a sample of 18 participants was selected who were considered to be

representative of the population. However, at the end a total of only 15 participants were interviewed, due to the unavailability of three participants in one branch which implies that the researcher has selected the sample from five branches instead of six branches.

From a list of participants at each branch (stratum), the researcher selected systematically every fifth employee living with HIV who had disclosed his/her HIV status in the workplace.

Data were collected by using in-depth interviewing. Greeff (2005:293) believes that the root of in-depth interviewing is an interest in understanding the experiences of other people and the meaning they make of those experiences. The researcher's desire to understand the experiences of employees living with HIV in the workplace after they have disclosed their HIV status prompted the use of in-depth interviews as a suitable data collection method. Thus one central question was put to all participants, formulated as follows: **How would you describe your daily experiences of living with HIV after you have disclosed your HIV status in the workplace?**

A digital voice recorder was used with the permission of the participants to record the interviews. Each file was given a code number and saved in a compact disc. In-depth interviews allowed the participants to describe their own experiences, while the researcher was able to obtain an in-depth understanding of the meaning of living with HIV in the workplace. The collected data were analysed according to the process as described by Creswell (in De Vos, 2005:334-339).

A detailed description of the research methodology used in this study will be given in Chapter 3.

## **1.6 Feasibility of the study**

The study was feasible based on the issues discussed below:

- **Costs:** Three of the branches of organisation Alpha are in Gauteng and therefore minimal travelling costs were involved. Travelling was only required to two coastal regions. Although some participants required the interview to be done off-site, minimal costs were incurred.
- **Time:** The participants chose a time that was suitable for them, mostly after working hours. Conducting interviews after working hours allowed for flexibility and both the researcher and the participants were not pressured to finish on time for the participant to go back to work.
- **Permission:** The researcher submitted a proposal to organisation Alpha to conduct the study and written permission was granted.
- **Availability:** All participants were in permanent employment of organisation Alpha, thus availability was guaranteed.

## **1.7 Ethical aspects**

Ethics are defined by Strydom (2005:57) as a “set of moral principles which is suggested by an individual or group, is subsequently highly accepted, and this offers rules and behavioural expectations about the most correct conduct towards experimental subjects and participants, employers, sponsors, other researchers, assistants and students.” Ethics is therefore the appropriateness of a researcher’s conduct or behaviour in relation to the rights of those who are participants of the study or who are affected by the study.

In this study the ethical issues described below were taken into consideration.

### **1.7.1 Informed consent from participants**

Neuman (2000:96) states that informed consent is a fundamental principle of ethics. Consent ensures that participation is voluntary. Participants should give consent and make an informed decision to participate. This consent should contain a brief description of the purpose and procedure of the study, a statement of risk involved with



participation, guaranteed anonymity and confidentiality of the records, and the identification of the researcher.

Strydom (2005:59) agrees with the above-mentioned author that consent to participate in a research study should be freely given and the participants should understand fully what the research is all about. Participants should have full understanding of their rights to participate or withdraw at any given stage of the study and how the data collected are going to be used. Any deception on the side of the researcher will be unethical.

In this study the researcher informed the participants about the purpose and the procedure and also the advantages and disadvantages of the study. The participants were provided with consent forms to sign before the start of the data collection process and they were also informed that they could withdraw from the study at any time without stating reasons. The consent forms reflected the researcher's name, the fictitious name of the organisation, possible advantages and disadvantages of the study and the utilisation of a voice recorder. It was also explained to the participants that the data would be kept for a period of 15 years at the Department of Social Work and Criminology at the University of Pretoria.

### **1.7.2 Confidentiality and anonymity**

According to Strydom (2005:63), confidentiality imposes a strong obligation on the researcher to guard information given by participants that is confidential to them. The interviews were conducted in a safe and private place outside the office after working hours. The researcher assured the participants of confidentiality and anonymity, as failure to honour their confidentiality and anonymity could result in harmful repercussions for the person whose openness has allowed the researcher to identify a certain point to explore. The data have been kept strictly confidential from the public. The information was not released in any way that could link specific individuals to any response. In order to protect the identity and the image of the organisation under study, the researcher used a fictitious name in reporting the findings for publication.

### **1.7.3 Deception**

Neuman (2000:95) states that deception is when the researcher tells half truths or lies about the purpose of the study. The rights of the person who participates in research are of crucial value. The researcher should never misrepresent the risks involved in a study. In this study the identity of the researcher, the purpose and procedure, as well as how the results would be presented were clearly stated in the informed consent letter and as an opening statement of interaction during the interviews.

### **1.7.4 Action and competence of the researcher**

Strydom (2005:63) states that researchers are obliged to ensure that they are competent and adequately skilled to undertake the proposed study. If the researcher or field workers are not adequately qualified or poorly supervised during a study, this can cause unethical behaviour.

For the purpose of this study the researcher has done a thorough study on the subject matter, and on the values, norms and cultural background of the participants to avoid psychological and emotional harm or value judgment, as the topic has moral, value, cultural and social factors involved. The researcher is also knowledgeable about research methodology and has done the study under the supervision of a skilled and professional supervisor.

### **1.7.5 Debriefing of participants**

Strydom (2005:66) states that the easiest way to debrief the participants is to discuss their feelings about the project immediately after the session or to send them a letter informing them of the basic intent or the results of the study.

In this study, debriefing was offered immediately after the interviews were completed, to clarify any misconceptions or misinterpretation of information. Debriefing was of great importance as HIV and AIDS affects all life dimensions of the person infected. To some participants the interview triggered buried emotions and emotions that the individual had

never dealt with. Such participants were referred for further psychotherapy to Independent Counselling and Advisory Services (referred to as ICAS).

### **1.7.6 Release or publication of the findings**

Strydom (2005:65) states that the researcher should do all he/she can to make sure that the report is as clear as possible and contains all the necessary information. The information must be formulated and conveyed clearly and unambiguously to avoid or minimise misappropriation by the participants, public and colleagues.

The findings in this study were released by writing a research report. The report was also made available to organisation Alpha and the University of Pretoria.

## **1.8 Limitations of the study**

The limitations of this study are presented below:

- Although HIV status disclosure was voluntary, it was a passive form of disclosure as the employees stated that they were very ill. Due to the fear of losing their jobs and benefits they felt that they had to disclose their HIV status. The implication thereof was that, although these individuals had disclosed their status, not all of them were ready to discuss their experiences and to participate in a research study.
- Another limitation was that participants were not always available at the time of appointment and thus new appointments were to be set which delayed the study.
- Although valuable data were collected, findings could not be generalised to the whole population due to the small sample of participants who were interviewed. Further studies need to be conducted.

## **1.9 Definition of key concepts**

Various key concepts which are relevant in the context of this study are set out below.

### **1.9.1 HIV**

The South African School Dictionary (2003:211) defines HIV as Human Immunodeficiency Virus which causes AIDS.

De Korte (1992:77) defines the Human Immunodeficiency Virus as “infection caused by one of the several related retroviruses that become incorporated into host cell DNA and result in a wide range of clinical presentations varying from asymptomatic carrier state to severely debilitating and fatal disorder.”

According to Evian (2006:6), the Human Immunodeficiency Virus is defined as the virus that attacks the immune system by destroying the T-helper cells, which are also known as CD4 cells of the body, thus causing Acquired Immune Deficiency Syndrome (AIDS).

The researcher defines HIV as the virus that attacks and slowly destroys the body's immune system with the result that life-threatening infections or diseases occur. The virus can be present in a person for several years before the person becomes sick.

### **1.9.2 AIDS**

Acquired Immune Deficiency Syndrome (AIDS) is a medical condition resulting from infection with HIV. HIV attacks and slowly destroys the body's immune system and gradually progresses to AIDS. At the AIDS stage, the individual presents with a number of opportunistic infections and the body can no longer fight any infections (Rehle, Shisana, Pillay, Zuma, Puren & Parker, 2007:2).

Evian (2006:119) defines Acquired Immune Deficiency Syndrome (AIDS) as an aggregate of signs and symptoms and illnesses resulting from a compromised immune system.

The researcher defines AIDS as a serious, progressive (often fatal) disease of the immune system that is transmitted through blood products and sexual intercourse by semen, which results in a compromised immune system.

### **1.9.3 Experience**

The South African School Dictionary (2003:159) defines experience as “what you learn from doing or seeing things or something that has happened to you”.

The Free Online Dictionary [sa] defines experience as the first hand knowledge of state, situations, emotions or sensations that an individual has lived or gone through.

The researcher defines experience as a feeling that can be emotional, intellectual or psychological which an individual may have in a given situation and is able to convey to others. These feelings may have emotional, intellectual and physical growth, maturity or destruction as a result, depending on how they are perceived and handled.

### **1.9.4 Disclosure**

The South African school dictionary (2003:132) defines disclosure as an “act of revealing a secret”.

The Free Online Dictionary [sa] defines disclosure as the submission of facts and details concerning a situation or business operation voluntarily.

For the purpose of this study, disclosure is defined as the process whereby an individual who has been diagnosed with HIV has decided to inform others confidentially.

### **1.9.5 Employee**

The South African School Dictionary (2003:156) defines an employee as a “person employed by someone”.

The Free Online Dictionary [sa] defines employee as any person hired by an employer to do a specific job or a specific defined relationship between an individual and an organisation.

For the purpose of this study, an employee is defined as an individual who enters into a written or verbal and a psychological contract to provide a service for another person or institution and is remunerated for the services rendered.

### **1.9.6 *Transport sector***

The researcher defines the transport sector as a government department including rail, ports, and aviation, freight, air and road agencies. This sector is responsible for the provision of all forms of transport under certain legislation as regulated. These organisations are all accountable to the Minister of Transport.

## **1.10 Division of the research report**

The structure of this research report is summarised below.

### **Chapter 1**

This chapter consists of a general introduction to the entire research with specific emphasis on the problem statement, goal and objectives of the study, a brief discussion of the research methodology used in this study, ethical aspects relevant to the study, limitations of the study, and definitions of key concepts relevant to the study.

### **Chapter 2**

Chapter 2 focuses on a literature review regarding the phenomenon of HIV and AIDS, the impact thereof on an individual and the workplace as well as the phenomenon of HIV status disclosure.

### **Chapter 3**

Chapter 3 focuses on a more detailed description of the research methodology used in the study as well as a description of the empirical findings.

## **Chapter 4**

In chapter 4 the researcher draws conclusions based on research findings and makes recommendations for action and further research on the topic.

## CHAPTER TWO

### HIV IN THE WORKPLACE WITH SPECIFIC EMPHASIS ON HIV STATUS DISCLOSURE

#### 2.1 Introduction

As the world enters the third decade since the first discovery of HIV and AIDS, the need for a collaborative, multi-sectoral response is becoming critical. Even though much has been done by the world over the past three decades, due to the prevalence of the pandemic more work is required. World Health Organisation (2009:11) mentions that during 2007, the new estimates indicated that 2.7 million people were newly infected with HIV, while 2 million people died of AIDS related diseases. This figure brings the total number of people living with HIV to 33 million globally. It is further highlighted that although there were about 7.9 million people in the developing countries who needed antiretroviral treatment, only 3 million people were receiving treatment. In this regard it is estimated that at the end of 2007 only 33% of HIV infected pregnant women had received antiretroviral treatment to reduce mother to child transmission.

The spread of HIV is still showing regional increase. Compared to the developed countries, sub-Saharan Africa is still the hardest hit region. In 2008, adults living with HIV and AIDS in sub-Saharan Africa were estimated at 22.4 million, new infections were at 1.7 million and there were 1.9 million deaths due to AIDS related illness (United Nations on HIV/AIDS, 2009:11). This scenario reflects that sub-Saharan Africa is home to 67% of people living with HIV and AIDS, with women constituting 50% of infected people. Therefore South Africa, as part of this region, continues to bear a disproportionate share of the global HIV burden.

Although the statistics are alarming and the devastating impact of HIV and AIDS is felt worldwide (Motepe, 2005:56), it is important to mention that current statistics show stabilisation of HIV infections. This is confirmed by the United Nations on HIV/AIDS (2010:16) which states that “in Sub-Saharan Africa, the HIV incidence has fallen by more than 25% between 2001 and 2009; yet, an estimated 1.8 million people were newly infected with HIV in 2009.” As indicated earlier, women and children are the most



vulnerable group. Of the prevalence of HIV infection, young people aged 15-24 years account for 45% of new infections worldwide (Rehle et al., 2007:487).

On the basis of the above information, it is however evident that HIV is still posing a huge health and economic problem to both developed and developing countries. Although the United Nations on HIV/AIDS (2010:16) refers to the stabilisation of the epidemic, the threat of high infection rate, particularly to young productive people in the age group of 15-24 years, has serious economic implications. It is also obvious that the slow pace of the government, and particularly of the South African government, to roll out the antiretroviral therapy, the poor state of state hospitals and the limited capacity of health professionals all contribute to the slow pace of mother to child transmission prevention, AIDS related deaths that could have been prevented, and failing prevention strategies.

Nonetheless, one of the most important threats lies in the societal views on the mode of HIV transmission which has been met with prejudice. What contributes to the challenge of curbing the rapid spread of HIV and AIDS, in addition to the societal prejudices, are the issues of stigma and discrimination, shame, guilt and fear which make HIV disclosure a legal and moral dilemma to those infected with HIV. The right to disclose or not to disclose an individual's HIV and AIDS status has from the early years of HIV and AIDS infection been linked to human rights, thus contributing to a low HIV status disclosure rate in highly educated individuals. These rights are often violated because of the presumed HIV status of individuals. Therefore, according to Viljoen (2005:13), the state is obligated to protect those with HIV and AIDS and promote the issue of HIV and AIDS human rights as people infected and affected by HIV and AIDS suffer both the burden of the disease and discrimination, stigmatisation and societal prejudices. In order to understand the phenomenon of HIV and AIDS, and specifically the impact of HIV and AIDS disclosure in the workplace, the focus of this chapter will be on the following aspects:

- conceptualising HIV and AIDS;
- the different stages of HIV;

- the prevalence of HIV and AIDS;
- risk factors associated with HIV and AIDS;
- the impact of HIV and AIDS to an individual and in the workplace;
- HIV and Human Rights; and
- HIV status disclosure.

## **2.2 Definition of HIV and its progression to AIDS**

### **2.2.1 *Human Immunodeficiency Virus (HIV)***

The Human Immunodeficiency Virus (HIV) is defined as the virus that attacks the immune system by destroying the T-helper cells which are also known as CD4 cells of the body, thus causing Acquired Immune Deficiency Syndrome (AIDS) (Evian, 2006:5).

According to Motepe (2005:59), HIV is predominately a sexually transmitted disease which is mainly transmitted by unprotected sexual intercourse with an infected individual. Viruses are obligate intracellular parasites, meaning that HIV cannot replicate itself outside the body cells. The virus is mainly found in the semen and, in very small proportions, from other bodily fluids (Evian, 2006:5).

According to Fan, Conner and Villarreal (2004:5), HIV belongs to a subgroup of retroviruses called lentiviruses which progress slowly to cause illness. A retrovirus can undergo an unusual biological process in which the genetic material in the form of single stranded RNA can be converted to double stranded DNA. This is attributed to the fact that it may take anything from 5 to 15 years from the time of infection to the stage where an individual can actually have AIDS (Evian, 2006:5). The progression of HIV can briefly be described in two phases, which are described below.

- *Latent Phase*

As mentioned earlier, HIV causes AIDS by attacking the T-helper cells known as CD4 cells. The latent phase is immediately after the HIV enters the human body. During this asymptomatic stage of HIV, the individual may develop a condition which is known as

Persistent Generalised Lymphadenopathy (PGL). PGL is a condition in which HIV continues to produce chronic painless swelling in the lymph nodes of the neck, jaws, groin and armpits (Fan et al., 2004:5, 15, 23; Motepe, 2005:61).

- *Constitutional Symptoms*

According to Calitz (2008:51), many patients develop low grade fever, chronic fatigue and generalised weakness, and a combination of food mal-absorption, loss of appetite and increased metabolism which contribute to AIDS wasting. It is during this symptomatic stage that an individual infected with HIV develops intermittent flu-like symptoms and at times a persistent cough which may result in an individual seeking medical help. At any time during the course of HIV infection, infected individuals may suffer from yeast infections known as thrush either in the mouth or on the genitals, open sores or ulcers, diarrhoea or other gastro-intestinal symptoms that may contribute to weight loss. The individual tests positive for HIV and the symptoms may vanish or progress to the late stages of the disease (Barnett & Whiteside, 2002:28; Motepe, 2005:63).

### **2.2.2 Acquired Immune Deficiency Syndrome (AIDS)**

It was mentioned earlier in the discussion that an individual infected with HIV can remain asymptomatic for 5 to 15 years or longer from the time of infection to the stage of an individual reaching the stage of AIDS. Barnett and Whiteside (2002:28) mention that when HIV enters the body and destroys the CD4 cells, the immune system is destroyed and thus opportunistic diseases and/or infections present with full blown AIDS.

The HIV infection may progress to a late stage of the disease where an individual may be diagnosed with full blown AIDS. At this stage of HIV infection, the infected person's body can no longer fight any infections (Rehle et al., 2007:2). Based on the information above, it is quite clear that HIV and AIDS is a dynamic medical condition. It is therefore a difficult and complex task to discuss the progression of HIV as only a medical condition without discussing other determinants associated with the phenomenon. Since its first discovery about 30 years ago, scientists and researchers have continually been

investigating a number of diseases and infections associated with HIV. Lately, some sexual transmitted infections, certain types of cancers and tuberculoses have been associated with AIDS (Evian, 2006:141, 145; Maboko & Mavundla; 2006:25; Rehle et al., 2007:199). This therefore implies that HIV and AIDS is still a rapidly developing phenomenon that requires more research in various aspects.

In order to understand the broader picture of the HIV and AIDS pandemic, the next section will focus on the prevalence of HIV and AIDS.

## **2.3 The prevalence of HIV and AIDS**

This section summarises the current status of HIV and AIDS infections globally, in sub-Saharan Africa, South Africa and, more specifically for the purpose and context of this study, in the South African transport sector. Although the HIV and AIDS pandemic still poses a health crisis, much has been done in response to the disease by all sectors in order to curb the spread of HIV and AIDS. Yet there is still more to be done.

### **2.3.1 Globally**

According to the report on the Global AIDS Epidemic (2008:32), the number of people living with HIV in 2001 was 19.7 million, the number of new infections was 2.3 million, and the number of AIDS related deaths was 1.4 million. Comparing these statistics with the statistics in 2004 where the number of people living with HIV was 39.4 million and the number of new infections was 4.9 million and AIDS deaths were 3.1 million (Motepe, 2005:68), it is clear that in 2004 the spread of HIV and AIDS was at its highest peak. In 2008, the number of people living with HIV was 33.4 million, while the number of new infections was 2.7 million and the number of deaths due to AIDS related illness remained at 2.0 million. According to the United Nations on HIV/AIDS (2009:7), the number of people living with HIV worldwide continued to grow in 2008, reaching an estimated 33.4 million. Therefore, the total number of people living with HIV in 2008 was more than 20% higher than in 2000 and the prevalence was roughly three times higher than in 1990.

However, there has been a decline noted in the rate of new infections in 2008 which may be attributed to the prevention programmes and the collaborative response by all sectors. Stabilisation of AIDS related deaths may be due to the roll out and availability of antiretroviral treatment (Versteeg & Murray, 2008:84). Despite all the measures taken, the infection rate is still alarmingly high in most countries. Sub-Saharan Africa remains the region with the highest infection rate in comparison to the rest of the world. The extent of the status of this area will be discussed below.

### **2.3.2 Sub-Saharan Africa**

As stated above, although HIV and AIDS seem to have stabilised in the rest of the world, according to United Nations on HIV/AIDS (2008:30), Sub-Saharan Africa is still home to more than 67% of the HIV and AIDS burden and half of this number is women. Sub-Saharan Africa accounted for 35% of new HIV infections and 75% of AIDS related deaths in 2007. It is further highlighted that the most vulnerable group is between the ages 15 and 24 years. Most individuals are at risk of being infected before the age of 25 years with the possibility of dying before the age of 35 years. This reduced life expectancy has also resulted in an increase in the number of orphans, some of them born with the virus.

In 2003, an estimated 25 million adults and children were living with HIV, while 2.2 million died of AIDS related illnesses in the region. In 2004 an estimated 3.1 million people were newly infected with HIV in the region (Motepe, 2005: 57). However, in 2008 the surveys reflected that 22.4 million people were living with HIV in Sub Saharan Africa, while new infections accounted for 1.9 million, and 1.4 million people died of AIDS related illnesses. This trend continued to 2009. Compared to 2001, there has been a slight decrease in the number of deaths and new infections. This slight improvement can be attributed to the increased availability of ARV treatment (United Nations on HIV/AIDS, 2010:2) as summarised in Table 2.1.

**Table 2.1 Sub-Saharan Summary of the HIV / AIDS Epidemic 2001 and 2009**

<b>Description</b>	<b>2001</b>	<b>2008</b>	<b>2009</b>
Number of people living with HIV	19.7 million	22.4 million	22.5 million
Number of new HIV infections	2.3 million	1.9 million	1.8 million
Number of AIDS related deaths	1.4 million	1.4 million	1.3 million

**(UNAIDS, 2010:2)**

The comparison between 2001 and 2009, particularly relating to the decrease in new infections noted in 2009, may be attributed to the preventative programmes that are provided in the different sectors, advanced medical treatment, and improved scientific and social research. The stabilisation of the death rate during the same period may be due to the provision of antiretroviral treatment (Poku & Whiteside, 2006:254). It is clear that with the provision of antiretroviral treatment and the prevention of mother to child transmission, the number of people living with HIV will continue to grow and AIDS related deaths decrease in the next 10 years. This will be due to the effects of the treatment which prolong the life of the infected individual (Poku & Whiteside, 2006:254).

South Africa continues to bear a disproportionate share of the global burden, and so the next section will focus on the prevalence of HIV and AIDS in South Africa.

### **2.3.3 South Africa**

South Africa as a developing country bears the largest burden of HIV and AIDS. According to United Nations on HIV/AIDS (2009:19), in the past HIV surveillance

focused on anonymous epidemiological designated sites, for example Ante-natal care clinics. However, since 2001 complementing the epidemiological designated sites was the increase in population-based surveys, for example Voluntary Counselling and Testing and Prevalence surveys in the workplaces. These new developments permitted a more accurate assessment of trends over time, particularly in South Africa as a developing country which bears the largest burden of HIV and AIDS (Simbayi, 2009:5).

Tracking the trend of HIV infection from 1990 to 2009, it is evident that the HIV epidemic has been escalating from its lowest in 1990 (ICAS, 2009:3). Based on the statistical data of HIV prevalence in South Africa between 1990 and 2009, HIV infections have been fluctuating from 0.7% in 1990 to 30% in 2005, which then went down to 16% in 2009. The statistics indicate that the infection rate amongst females ranges between the ages of 15-34 years, with the highest peak at 25-29 years with a 33.3% HIV infection in females, whilst with males the infection rate ranges between 25-54 years with the highest peak infection standing at 35-39 years (Motepe, 2005:57; Visser & Mundell, 2008:66).

The Department of Health, as cited in Visser and Mundell (2008:66), indicates that the total number of people living with HIV in South Africa was estimated between 5.7 million and 6.2 million. The HIV prevalence, disease progression and mortality vary by province with the highest prevalence in KwaZulu- Natal and Mpumalanga, and a low prevalence in the Western Cape and Northern Cape as summarised in Table 2.2 below.

**Table 2.2 South African Provincial HIV Prevalence**

Province	HIV Prevalence
Mpumalanga	23.1%
KZN	21.9%
Orange Free State	19.2%
North West	18.0 %
Gauteng	15.8 %
Eastern Cape	15.5 %
Limpopo	11.0 %
Northern Cape	9.0%
Western Cape	3.2 %

**(Visser & Mundell, 2008:66)**

For the purpose of this study it is important to note that KwaZulu-Natal and Mpumalanga with the highest prevalence of HIV make up the road transport corridor to gain entrance from neighbouring countries, as well as an exit to these countries for heavy load trucks. This implies that the transport sector is one of the most risky industries in South Africa in terms of exposure to the HIV and AIDS pandemic. The following section will thus focus on a brief discussion of the extent of the HIV and AIDS pandemic in the South African transport sector.

#### **2.3.4 Transport Sector in South Africa**

The transport sector is one of the largest sectors in South Africa with high mobility amongst its workers. The transport sector constitutes rail, roads, airfreight, airlines, transport agencies and ports. Transportation of goods and people extends beyond the borders of South Africa. Due to the nature of their work, a high proportion of the



transport sector workers have thus a high risk of HIV infection. This is confirmed by van Aardt (2008:15) who mentions that more than 50% of the transport sector employees live with HIV. These statistics correlate with a study done by the Independent Counselling and Advisory Services (2009:3) in Organisation Alpha in its six branches in Gauteng, KwaZulu-Natal, the Western Cape and the Eastern Cape. This study showed further data which is consistent with the national demographics, namely: (i) the HIV and AIDS risk is significantly different for males and females, (ii) that female HIV prevalence peaks between the ages 20 to 24 years of age, and that (iii) the highest HIV prevalence in organisation Alpha is found in KwaZulu-Natal, Gauteng and Mpumalanga with the lowest rate in the Western Cape (Shisana, Rehle, Simbayi, Parker, Jooste, Pillay-van Wyk, Mbelle & Van Zyl, 2008:29).

In conclusion it can thus be stated that, since HIV's first discovery in the 1980s, both globally and locally, the trends reflect an escalation of the number of infections and AIDS related deaths. During the first decade, between 1990 and 2000, the epidemic reached its peak, while scientists, governments and civil society were trying to find a solution for the pandemic. HIV and AIDS have been the centre of political agendas and many debates have been held, but without decisive actions. In South Africa, HIV and AIDS were met with denial and a lack of political will to take action (Forsyth et al., 2008:74).

However, it is during the second decade between 2006 and 2008 where stabilisation and a slight decrease of deaths related to AIDS and HIV infections have been noted (United Nations on HIV/AIDS, 2008:30). This slight improvement can probably be attributed to the change in the political will of government, collaborative preventative programmes by all sectors and activism around issues of HIV and AIDS by civil societies (RSA President, 2009). It is not denied that much is done in response to HIV and AIDS. However, much still needs to be done. It is also evident that the provision of antiretroviral treatment and prevention of Mother to Child Transmission has contributed significantly to the reduction of mother to child transmission and subsequently to the stabilisation of AIDS related deaths in children (Evian, 2006: 225; United Nations on HIV/AIDS, 2010: 16).

However in order to stimulate the decrease in HIV and AIDS related illnesses and deaths, it is important to take note of the risk factors associated with the spread of HIV as discussed in the following section.

## **2.4 Risk factors associated with the spread of HIV**

Rehle et al. (2007:194), as well as Visser and Mundell (2008: 62), mention that the prevention of HIV and AIDS related illnesses and deaths is constrained by the following socio-economic factors:

- culture and social norms;
- stigma and denial;
- poverty;
- labour related migration;
- gender based violence; and
- HIV and human rights.

These socio-economic risk factors associated with the spread of HIV and AIDS will briefly be discussed and their relation to the phenomenon of HIV status disclosure in the workplace.

### **2.4.1 Culture and social norms**

Different authors highlight the fact that certain cultural and social norms and practices are risk factors in the spread of HIV and AIDS. Leclerc-Madlala (2003) and Simbayi, Charveau and Shisana (2004:615) note for instance that gender inequality plays a major role in the spread of HIV in many societies where women are accorded a lower status than men. It is based on the assumed lower status of women that women cannot make decisions on their own sexual activities or negotiate for condom use. In certain cultures there is a cultural belief and behavioural practice, namely the rites of marriage.

According to this cultural practice, a husband who married an infertile woman can have sex with the sister of his wife in order to have children to carry the family name. Although this is an acceptable cultural practice in certain ethnic groups, this may be a risk factor in the spread of the HIV pandemic because of the multiple sexual partners. Other examples of cultural practices which are risk factors are; (i) the practice of polygamy, (ii) the prohibition of sex during breast feeding, (iii) fertility obligations and (iv) the superstitious belief that if an infected man has sex with a virgin he will be cured. These cultural beliefs and norms have the potential to perpetuate the spread of HIV and AIDS as they result to multiple concurrent sexual partners and sabotage preventative measures.

Some cultures, social norms and practices were important in the olden days, for instance, the practice of polygamy and the bridal price; these were important cultural practices because they were respected and perpetuated according to certain values. The reasons behind these practices were said to constitute bonding between two families and a mark of appreciation to the women's family and prevention of illegitimate children respectively. These days the "bride price" has now become akin to the purchase of wives and a justification for the subjugation of women and as such contributes to the spread of HIV. Human Rights Watch (2003:19) and Norman, Chopra and Kadiyal (2005:3) mention that the customary payment of bride price is now assumed to be giving the husband proprietary rights over his wife, allowing him to treat her more or less like a possession and therefore contributes to the spread of HIV.

There is a general consensus by a number of researchers that the disclosure of an individual's HIV status has a profound and disruptive effect on family structures and family members. These disruptions may affect the family's problem solving capabilities, resulting in family dysfunction (Goudge, Ngoma, Manderson & Schneider, 2009:100). However, the extent and duration of family disruption is influenced by history and strength of family bonds, previous experiences and coping skills in relation to other life-threatening illnesses, attitudes, knowledge and perceptions on HIV and AIDS (Barnett & Whiteside, 2002:258; Goudge et al., 2009:96).

Furthermore, the degree of knowledge and the myths around HIV and AIDS and the social construction of what HIV and AIDS is by the communities, are guided by the social, religious and cultural beliefs about HIV infection. It is therefore according to these social constructs that people who tested HIV positive are blamed and accused of bringing the disease upon themselves or are said to have been cursed for sinning and this contributes to the stigma as discussed below (Forsyth et al., 2008:74).

#### **2.4.2 Stigma**

Padayachee (2005:34) defines stigma as the situation when a person is viewed differently or as one who does not belong to the society. Viljoen (2005:23) further describes stigma as a complex process involving interrelated concepts like gender, race dynamics and social class, whereas Mbonu, van der Borne and De Vries (2009:2) agree with these definitions and further postulate that stigma can be defined as marks of disgrace, discredit or infamy. Hence, stigma has great influence on the spread of HIV and AIDS. At times there is labelling, gossip and stigmatisation around HIV infected individuals. Hence stigma is one of the leading factors that contribute to the fear of disclosure of one's HIV status (Kalichman & Simbayi, 2007). It is established that stigma may result in blaming, labelling, exclusion and isolation of those individuals infected and/or affected by HIV. According Padayachee (2005:34), the HIV infected person does not only deal with a life-threatening illness, probable death and HIV related symptoms, but also with change in body image, decisions about disclosure, mistrust, relationships and stigma.

It seems therefore there is a general consensus that stigma represents a construction of deviation from some ideal or societal expectations. It is established that HIV related stigma has multiple individual and systematic disadvantages. Mostly women are economically oppressed and blamed for infecting their husband. In certain circumstances some marriages end in divorce or separation with the HIV infected wife, parents and relatives abandoning and or resenting their children and relatives who tested HIV positive. There is no doubt that HIV related stigma is still a considerable contributing factor to individuals delaying or failing to start antiretroviral treatment and

pregnant women being too scared to access maternity health services, thus failing to prevent risk of mother to child infection (Gillespie, 2003:34).

It is therefore evident that the HIV and AIDS stigma is a social construct, which has a significant impact on the life experiences of those individuals who are affected and infected with HIV and AIDS which may lead to overly discriminatory behaviours. As a social phenomenon, HIV and AIDS related stigma can cause delays in testing, poor treatment adherence and greater numbers of new infections as argued by a number of researchers (Goudge et al., 2009:94; Mbonu et al., 2009:3, 4).

When people who have tested HIV positive are too scared to disclose their HIV status due to stigma there is a serious risk of spreading HIV, a situation that could have been prevented from occurring, and thus the HIV infected individuals die in silence (Mbonu et al., 2009:94; Viljoen, 2005:36, 37; Goudge et al., 2009:94.95; Greeff, Phetlhu, Makoe, Dlamini, Holzemer, Naidoo, Kohi, Uys & Chirwa, 2008:132).

Linked to stigma, in developing countries particularly in rural areas where there are high levels of illiteracy and a lack of economic resources, individuals are likely to engage in risky sexual behaviours for survival and thus there is a high risk of spread of HIV infection. Furthermore, stigma is seen as a violation of human rights as discussed in the section below.

### **2.4.3 HIV and Human Rights**

Although much has been done in terms of regulating all sectors of employment and customary laws discriminating against women, it is unfortunate that the application and implementation of these laws are not monitored. There is evidence for instance in the fact that, recently, polygamy has been legalised under both customary and Islamic laws. Customary practices vary from one ethnic group to another and because of this, violation of women's rights in marriage is viewed as a family matter and frequently it is not reported to the law enforcement officials, thus contributing to women's vulnerability to HIV infections (Human Rights Watch 2003:19). This practice is not so different from the labour regulations that regulate employment practices. According to the Employment Equity Act 55 of 1998 section 9: "Regulations *regarding the protection of*

*individuals living with HIV and related matters, people living with HIV should be treated with dignity, equally and shall not be unfairly discriminated against in the workplace”.* Therefore an individual regardless of his/her HIV status shall not be excluded from employment, promotion and education. Judge Ngcobo made reference to this legislation, as cited in Grogan (2003:153), in the South African Airways (SAA) versus Hoffman case that “people living with HIV constitute a minority and are faced with systematic disadvantage and discrimination, they are victimised, stigmatised and marginalised”. In this case, Hoffman was denied employment due to his HIV status which had nothing to do with the operational requirements of the job.

According to Grogan (2003:259) the Hoffman versus SAA case was the first case taken to a court of law for typical discrimination based on an individual’s HIV status after he went for interviews and medical test that revealed his positive HIV status. Gathering from the above discussion, although this case was won, there are similar cases in the workplace that are not brought to court. These legal issues contribute to individuals’ fears to test in workplace initiated HIV tests. It implies that the individual who has tested positive may remain silent about his/her HIV status and engage in risky behaviours which contribute to the spread of HIV.

#### **2.4.4 Poverty**

Forsyth et al. (2008:80) and Poku and Whiteside (2006:254) state that although poverty is not a direct cause of AIDS, studies have shown a direct link between poverty and the spread of HIV. The link is due to different factors of which the following are the most relevant ones:

Women’s status: There is scientific evidence as discussed in the previous sections that women are the most vulnerable group to HIV infection based on their subordinate role in society. In most developing countries, women are less educated and poor and thus they lack power to negotiate safe sex.

The sugar daddy concept: young girls sell sex in exchange for money and gifts. Unequal distribution of income, orphans and vulnerable children and child-headed families lead to these vulnerable children seeking a monetary reward from elderly men.

These circumstances perpetuate the spread of HIV and AIDS, not to mention the misery brought to children who have lost one or both parents due to HIV and AIDS (Human Rights Watch, 2003:32; Motepe, 2005:140).

Poor public health system: as the pandemic is becoming more mature and affecting a greater proportion of the population, policy makers are facing new challenges of curbing HIV. There is no doubt that HIV and AIDS will have a long-term impact on the reduction of health care provision and other social services caused by infected health care workers. Poku and Whiteside (2006:253) note that the AIDS pandemic is a long-term event with an impact that will unfold over many decades rather than months (Baylies & Bujra, 2000:13; Forsyth et al., 2008:81). Furthermore, Datta and Njuguna (2008:95) highlight the fact of increased medical costs which occur when testing HIV positive. Due to envisaged lifestyle changes, job losses due to ill health, and/or the death of a bread winner, families may find themselves in financial difficulties which may lead to poverty.

Migration due to poverty: Baylies and Bujra (2000:13) further highlight the fact that the remote rural areas where poverty is rife, for example in KwaZulu-Natal, Mpumalanga and the Eastern Cape, are amongst the hardest hit by HIV. It is due to poverty that people from the poor economic provinces and neighbouring countries such as Zimbabwe and Mozambique, to mention a few, migrates to Gauteng which is known as the economic hub of South Africa. It is therefore migration due to poverty that contributes to the high HIV prevalence in Gauteng as compared to the Western Cape.

Hence the link between poverty and HIV risk may be perpetuated by the need to move in search of work. Although migration is not an inherent determining factor in the increased risk of the spread of HIV and thus on its own not a risk factor, the circumstances associated with mobility, for instance a migrant worker who left a wife at home and has another sexual partner in the city increases the vulnerability to HIV infection. This is discussed in the next section.

#### **2.4.5 Labour related migration**

The mining industry represents the most significant portion of labour related migration in South Africa, because mine workers have been recruited from beyond the borders of South Africa. The movement and interaction of people across borders contribute directly to the spread of HIV and AIDS. In this regard, Kalichman et al. (2007) mention that migrant workers are more likely to have more than one partner than non-migrant workers, because they leave their wives back home and they are likely exposed to engaging in risky sexual behaviours.

The second industry with high mobility is the transport sector. Transport workers, particularly truck drivers who transport goods across the country and beyond the borders of the African states and stay for longer periods away from home, are also contributing to the spread of HIV and AIDS. Earlier, in the discussion on the prevalence of HIV and AIDS, it was mentioned that truck drivers engage in risky sexual behaviours with sex workers (Rehle et al., 2007:195; Davis, Deysel, de Bruin & Strydom, 2002:25).

However, the tide has turned; migration of the middle class and professionals has been on the rise in the recent years from province to province and between countries. Due to the nature of the work done by this group, deployment in other countries at times leaving families behind and frequent mobility to conferences, increases the likelihood to risky sexual behaviours and thus the spread of HIV. In this regard Simbayi (2009:4) as well as United Nations on HIV/AIDS (2009:36) confirmed the existence of the underlying behavioural risk factors for HIV infection in the legal services, the education sector and amongst security guards. These new findings are reflecting that HIV and AIDS should no longer be regarded as a low socio-economic phenomenon, as it has been consistently viewed during the early stages of the pandemic. Labour migration is a reality amongst all socio-economic classes and definitely a risk factor in the spread of HIV and AIDS.

#### **2.4.6 Gender-based violence.**

Gender-based violence is a global phenomenon and has been viewed in HIV literature as a leading cause of the spread of HIV infection and AIDS (Human Rights Watch,



2003:2). Domestic violence has rendered women of diverse religions, ethnic groups and economic classes vulnerable to HIV infections. The phenomenon of gender violence is not an isolated and aberrant act, but arises from and forms part of the women's life. In the context of cultural and social norms, women are viewed as subordinate to their husbands, and their low economic status, customary laws, culture and societal pressure to tolerate violence all result in some women from certain cultural groups experiencing sexual violence in their marriages and relationships (Human Rights Watch, 2003:2, 3, 4, 9).

In the environment where HIV and AIDS stigma remains at high levels, fear of violence, resentment and physical abuse have prevented most women from accessing HIV testing services, counselling and/or treatment and thus they die in silence. The lack of power to negotiate safe sex, economic autonomy and education has prevented some women from escaping abusive relationships and this renders them vulnerable to HIV infection (Human Rights Watch, 2003:19; Shisana et al., 2008:29; Rehle et al., 2007:195).

For instance, marital and date rape increase the vulnerability of women to HIV infection. Furthermore, socio-economic and legal factors also largely increase to this vulnerability where women are unable to protect themselves. This seems to be perpetuated by inadequate and discriminatory labour laws which contribute to the oppression of women in the society and thus also to the spread of HIV and AIDS (Human Rights Watch, 2003:28).

## **2.5 Impact of HIV on the individual**

The impact of HIV and AIDS on the individual is multifaceted and devastating. The researcher will only briefly discuss the physical, psychosocial and financial impact on the individual.

### **2.5.1 Physical impact**

From the time the virus enters the individual's body, some changes take place. As the body's immune system is compromised, opportunistic conditions invade the body and the individual starts living with life-threatening illnesses. According to Hall (2004:111, 115) and Motepe (2005:99), the body becomes progressively weaker due to the following physical implications:

- gastro-intestinal disturbances characterised by vomiting and diarrhoea;
- chest infections which may lead to difficulty in breathing characterised by certain types of pneumonia;
- certain types of tuberculosis which may lead to paralysis;
- skin cancers leading to a change in the skin colour which may have a tint of yellow or grey; and
- change in body weight, colour and texture of hair and, at times, loss of hair which alters the body image of the individual and lowers the self- esteem and confidence, which in turn affects sexual relationships. Individuals who desire to fall pregnant but who tested HIV positive might be scared to fall pregnant.

Due to physical illness, the HIV status and its impact the individual may reach a state of psychological ill health (Fan, Conner & Villarreal, 2004:5, 51) as described in the next section.

### **2.5.2 Psycho-social impact**

The psycho-social impact of HIV on people diagnosed with HIV should never be underestimated. People diagnosed with such a life-threatening illness in combination with cancers and a change in body image will react with fear, anxiety anger towards those perceived to have infected them, blame, withdrawal, grief and even depressive disorders. The fear associated with HIV and AIDS may emanate from the stigma associated with HIV and AIDS, the loss of a spouse due to death, the loss of a child if the individual was pregnant at the time of HIV diagnosis, divorce, resentment towards a

spouse who tested positive, fear of own death, and loss of productive time or work hours due to frequent ill health which may lead to unemployment (Greeff et al., 2008:12; Maboko & Mavundla, 2006:28). Doyal and Anderson (sa:95) state that many women diagnosed as HIV positive talk about how difficult it is to make ends meet and how fear prevents them from making sound decisions on their future; they are psychologically paralysed.

On a social level, one of the most serious consequences of HIV is the fact that people diagnosed as HIV positive experience stigma and discrimination. Although the phenomenon of HIV and AIDS has existed for nearly 30 years, and although there are laws protecting the rights and dignity of People Living with HIV/AIDS (PLWHA), these people still experience discrimination (Doyal & Anderson, sa:97). In most communities, families and workplaces, there is evidence of discrimination and rejection by others including family members and friends. Women in particular are discriminated against even by their own husbands and suffer divorce and abuse. Some people are even evicted from their own homes.

Discrimination becomes more frightening when it happens in the workplace: a silent form of resentment to those who disclose their HIV status to their colleagues or supervisors. The indirect discrimination in the workplace may come in the form of excuses for non-promotion, a decline in training opportunities on the basis of the individual's ill health, or poor attendance (Mbonu et al., 2009:98; Goudge et al., 2009:75). Although poor attendance leading to poor performance may represent fair grounds for denial of growth opportunities in the workplace, the employer has an obligation to take into consideration the individual's previous performance and attendance records and failure to do so might constitute indirect discrimination. However, according to Padayachee (2005:35), there is evidence that there has been a change of attitude towards people living with HIV and AIDS due to the number of people affected and infected by the disease. Public education by non-governmental organisations, government and civil society has also contributed to the change of attitude.

The stigma, fear, discrimination and ill health that may result in poor work performance and attendance as the individual may be incapacitated, may lead to leave without pay, reduction in salary or no income at all which will have an impact on the individual's financial status as indicated below.

### **2.5.3 Financial impact**

Motepe (2005:129, 161) states that the HIV and AIDS epidemic reduces the household's capability to produce and purchase food, depletes their assets and resources, and exhausts social safety nets. Furthermore, there is an increased demand for medical care and treatment like expensive antiretroviral treatment, funeral expenses when a family member dies, and a change in nutritional needs; these may result in a rise of the household expenditure. The financial impact is thus devastating, especially when both parents die due to AIDS and children are left behind with the financial burden that becomes too much. These children may end up leaving school to look for work or ultimately engaging in crime. Earlier in the previous discussions, poverty was highlighted as both the consequence and risk factor in the spread of HIV and AIDS in most countries. An additional consequence of HIV and AIDS for the individual is the ongoing illness which requires medical intervention. By its nature the burden of care for the HIV affected individuals and families require additional financial resources (Datta & Njuguna, 2008:95).

## **2.6 The impact of HIV in the workplace**

According to Padayachee (2005:20) HIV and AIDS can have a long-term crippling effect on any economy. Therefore, the HIV and AIDS pandemic is considered to be the single most strategic dilemma the workplace, including government, has ever faced in the new millennium. It is primarily due to the high rate of HIV among females in the age group 20-24 years and 20-49 years in males, who are the productive age group. The apparent economic impact on the workplace will be discussed in the sub-section below.

### **2.6.1 Absenteeism**

Robert et al (1996), as quoted by Barnett and Whiteside (2002:254), postulate that absenteeism related to HIV accounts for 37% and AIDS for 15%. These absenteeism rates are not only related to individual employees who have tested HIV positive, but also to employees who have to care for sick family members or need to attend funerals. During the stage of AIDS when individuals suffer from debilitating opportunistic conditions, for example disseminated tuberculosis which affects approximately 8-10 million AIDS patients, individuals can be on prolonged sick leave which may exceed 30 days which implies tremendous financial implications (Barnett & Whiteside, 2002:245, 247; Dickinson, 2004:42,79 ).

According to Calitz (2008:3), HIV is the largest contributor to absenteeism in the workplace. An individual who is living with HIV is three to four times more absent than a HIV negative employee. This trend is associated with the number of factors that affect HIV infected employees. In most cases as soon as the individual tests HIV positive, he/she will experience shock, denial and other emotional reactions, and may decide to stay away from work to avoid being stared at by other employees. In some incidents, the individual may have fears associated with the HIV stigma particularly when he/she starts to develop signs and symptoms of illness.

Although not much research has been done on occupational accidents and injuries associated with HIV, it is observed that HIV affects the neurological functioning of individuals. These individuals may be prone to occupational injuries and accidents. This phenomenon could be the gap in HIV related absenteeism that needs to be researched in the future. Continuing on the topic of absenteeism, companies lose substantive amounts of money on absenteeism, which affects productivity and the staff morale of those individuals that have to take over the sick employee's work.

### **2.6.2 Financial impact on the workplace**

Davies, de Bruin, Deysel and Strydom (2002:30) estimate that for every 1000 natural deaths that occur in a year, 88 of them are highly skilled workers, 176 are skilled workers and 308 are semi-skilled workers. These authors further note that South African

companies lose 4% of their employees to HIV and AIDS per year. Sunter (2000), in Davies et al. (2002:30) elaborates on the financial impact on the organisation by stating that for each employee who has died of AIDS related illnesses, a company will lose R1 million in respect of medical costs, absenteeism, training, recruitment and placement, and low productivity. The cost implications of HIV and AIDS in the workplace can be classified into direct and indirect costs.

- ***Direct costs***

The direct costs are costs on staff salaries, operational costs and allowances. These costs are visible and include those cost that are used for the families of employees and through Corporate Social Investment initiatives. According to Bower (2002:17) and Barnett and Whiteside (2002:253), there will be greater competition for skilled workers as more and more skilled workers die of AIDS related illness. Therefore, remuneration costs will increase and this will lead to an increase in wage differentials. Furthermore, government taxes increase as government spending on health and welfare resources increases and in all companies, an increase in operational costs may be incurred to run the workplace HIV and AIDS programmes. Some costs are hidden as the company may not feel the impact in the short-term, but rather in the long-term as discussed below.

- ***Indirect costs***

Indirect costs are costs due to the loss of productivity through morbidity and mortality. It is therefore important to mention that HIV and AIDS will not only affect productivity but also competitiveness and profitability amongst companies. As related illness and death target individuals who are still at their productive age, companies lose substantive working years and time (Barnett & Whiteside, 2002:253). Bruton (2000), as cited by Bower (2002:26), states that when one knows the total exits from companies due to HIV and AIDS, it is possible to anticipate the HIV and AIDS related labour turnover per year at 2.0% escalating to 15.9 % over a period of 10 years.

The researcher is of the view that the other form of indirect economic impact is the costs related to medical benefits and insurances. Even though these are paid through medical aid companies, the rising medical related claims influence the increase in annual

premiums paid by the company. It is also important to note that escalating costs to pension and death payouts have an impact on the insurance premiums.

The above-mentioned clearly indicates the seriousness of the scourge of HIV and AIDS in the workplace, particularly if organisations do not effectively respond by putting programmes in place to address and mitigate the impact.

Figure 2.1 below summarises the impact of HIV and AIDS in the workplace (Barnett & Whiteside, 2002:254, 255, 256; Mapolisa, Schneider & Stevens, 2004:161).

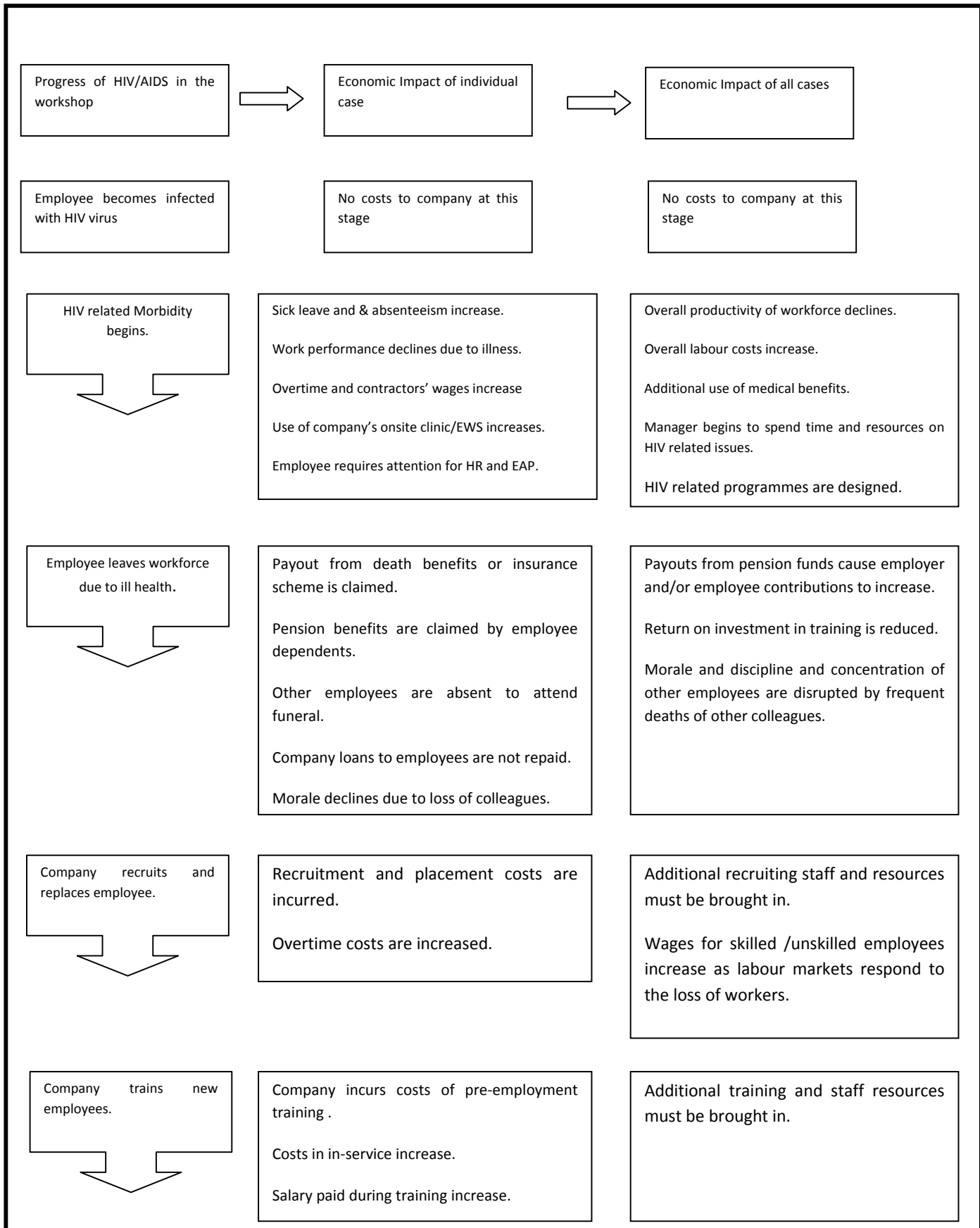




Figure 2.1 above illustrates that at the initial stages when an employee is diagnosed with HIV, there are no costs to the company until the HIV related illness begins. It is during this stage of early morbidity that sick leave and absenteeism increases. The individual's work performance declines due to illness. The company may resort to allowing other workers to work overtime and/or employ contract workers which will have an impact on wage increases.

Although this phase affects an individual employee, the overall productivity of the workforce declines. The overall labour costs and use of medical benefits increases. The managers may at this time require spending time and other resources on HIV management (Bower, 2002:26; Barnett & Whiteside, 2002:254).

As the disease progresses, the individual employee may leave the workplace due to ill health. There may be incapacity or death. The employee may claim from the pension fund or the members of family may claim from the death benefits if the employee dies. Subsequently, other employees will be absent to attend the funeral and morale declines due to loss of a colleague. Pension and death payout increases the company premiums paid to the insurer and the company loses skilled and experienced employees.

It is thus clear that HIV infection is associated with death, hopelessness and stigma in both communities and in the workplace. However, these challenges could offer an opportunity for the workplace to develop interventions to reduce HIV related stigma and thus mitigate the impact of HIV and AIDS in the workplace if employees who tested positive were to be encouraged to disclose their HIV status. The limited data available on workplace HIV status disclosure in South Africa, suggest that non-disclosure may reduce emotional support to cope with HIV positive status and the capacity to introduce behavioural change models in the workplace. In relation to this, it is important to discuss the phenomenon of HIV status disclosure in the workplace.

## **2.7 The phenomenon of HIV status disclosure**

Disclosure of a person's HIV status is one of the most sensitive issues in the field of HIV and AIDS. According to Doyal and Anderson (sa:98), relative success in establishing and maintaining a social life was linked to views about the disclosure of HIV status. Some people manage to sustain full social lives despite their diagnosis. But many feel that they have to protect themselves and their families by keeping their HIV status a secret. However, it is hard to sustain relationships that are based on lies. Hence at times people living with HIV prefer to live a separate life from those who are HIV negative. On the other hand, Greeff et al. (2008:311) and Kalichman (2009:92) mention that most people have disclosed their status to someone, often with mixed results. However, they agree with the above statement that individuals who are aware of their HIV-status are frequently confronted with the important, albeit difficult decision, of whether to disclose their HIV status to others or not.

Every individual has a right to privacy and dignity as stated in the Employment Equity Act 55 of 1998 section 9: "*Regulating the individual's right to confidentiality and dignity*". Unfortunately, this right to privacy is frequently ignored with regard to an individual's HIV status with painful consequences for the individual. In order to understand HIV status disclosure, the researcher will briefly discuss the following aspects:

- categories of HIV status disclosure;
- factors that influence the decision to disclose;
- the consequences of HIV disclosure; and
- HIV status disclosure in the workplace.

### **2.7.1 Categories of HIV status disclosure**

According to Greeff et al. (2008:313), HIV status disclosure is described in two main categories; voluntary disclosure and disclosure without consent as briefly discussed below.

### **2.7.1.1 Voluntary disclosure**

According to Greeff et al. (2008:313), voluntary HIV status disclosure is described as managed and concealment disclosure. In voluntary disclosure, the People Living with HIV/AIDS maintain control over the choice to disclose, to whom he/she should disclose, and whether he/she should fully or partially disclose. While managed disclosure is an individual's choice, this type of disclosure can be further divided into two categories as described below:

- *Active voluntary disclosure*

In active voluntary disclosure, the individual has a desire to disclose and will, out his/her own free will, choose to without any compelling reasons. In most cases individuals who have tested HIV positive find themselves isolated due to stigma, and in the quest to belong, they disclose to support groups. In support groups they share similar experiences of living with HIV (Visser & Mundell, 2008:66; Greeff et al., 2008:313).

- *Passive voluntary disclosure*

Passive voluntary disclosure is when an individual has no other choice but to disclose. In most cases this type of disclosure is common in the workplace. The individual faces disciplinary action due to poor performance and frequent illness and then discloses his/her HIV status with the hope to be accommodated.

Although this type of disclosure is voluntary, the individual may have not been ready to disclose. In the workplace, an individual may choose to disclose to the manager or supervisor hoping to be accommodated. When the desire to be reasonably accommodated in the workplace does not materialise, the opposite may happen; the individual may be stigmatised, discriminated and his/her status even disclosed on his/her behalf without consent (Viljoen, 2005:34, 35; Greeff et al., 2008:314; Visser & Mundell, 2008:67).

### **2.7.1.2 Disclosure without consent**

The second category of disclosure, namely disclosure without consent, is according to Greeff et al. (2008: 314) also known as mismanaged disclosure, where an individual's sero-positive status is disclosed without the individual's consent. The individual has lost control of the disclosure decision. Viljoen (2005:33) links disclosure without consent to a human rights violation and stigma. This type of disclosure is common in health care facilities by health care workers, and also in family situations where out of shock, fear and denial, family members may disclose to other family members or neighbours on behalf of the individual. In most cases involuntary disclosure can be the result of severe illness, usually in advanced stages of AIDS probably out of fear of death (Greeff et al., 2008:314).

Thus HIV and AIDS status disclosure is a process. The literature clearly reflects the impact of HIV on the individual and family, therefore the individual needs to accept his or her status before deciding to disclose. It is always advisable for individuals to disclose when they are ready to deal with whatever reaction they will receive from those they chose to disclose to. Living with a life-threatening condition is difficult enough without adding other emotional traumas like rejection, prejudice, stigma and being judged for moral reasons and the attitude of service providers like health care workers. With regard to health care workers, Viljoen (2005:68) postulates that health care workers are legally required to keep all personal information about a patient confidential. Particularly with the outbreak of HIV and AIDS, the Medical and Dental Board of the Health Professions Council of South Africa issued out a set of guidelines on how to manage HIV and AIDS disclosure. However, there are allegations that health care workers disclose HIV test results outside the professional framework of guidelines. When such an act happens, the doctor/nurse/patient relationship has been violated and as such the individual health professional has breached an ethical code of conduct.

The process of disclosure itself might be a very stressful event even in cases of positive outcomes. Therefore, there are factors an individual should take into consideration before disclosing his/her status, as discussed in the following section.

## **2.7.2 Factors that influence the decision to disclose HIV status**

According to Chandra et al. (2003), as quoted in Greeff et al. (2008:314), as well as Mbonu et al. (2008:3), there are several negative factors that may influence the decision to disclose. These include the fear of discrimination, the anticipated disruption of family and intimate relationships, threat to one's job security, and payment of insurance. As mentioned earlier in the previous discussions, an HIV positive person experiences fears of stigma, verbal and physical abuse, and fear about accessing care and support services, as well as the desire to protect significant others. In the workplace the factors that may influence disclosure may be related to the fear of losing one's job, not being promoted, being discriminated against, losing health and other employment benefits and the protection of one's occupational status.

On the other hand, Mbonu et al. (2008:70) also note that there are positive factors that may influence disclosure, such as the desire to establish support groups to share personal experiences with other individuals. Support groups have a major role to play in educating others on the true facts about HIV and AIDS. These support groups assist as a mechanism for empowerment.

Whatever positive or negative factors are involved, disclosing like any other action has consequences.

## **2.7.3 The consequences of HIV status disclosure**

Disclosure can have negative as well as positive consequences and it requires a great deal of courage. It is acknowledged that holding back the truth results in stress which negatively affects the physical wellbeing of an individual. The HIV positive person should, however, take note of both the negative and positive consequences of disclosure, as discussed in the following sub-section.

### **2.7.3.1 Negative consequences of disclosure**

One of the most important negative consequences of disclosure is stigma and discrimination. The social construct of HIV and AIDS, the perceptions of others, lack of knowledge, and the stigma attached to HIV and AIDS may even result in internalised

stigma which may contribute to a negative evaluation of self, a loss of self esteem and confidence, anxiety and social withdrawal. Furthermore, the blame associated with HIV status, character judgement and belief concerning promiscuity, may also lead to negative consequences of disclosure (Greeff et al., 2008:316). Kalichman and Simbayi (2009: 87-89) mention that other negative consequences of disclosure were associated with depression and lack of social support.

Based on the above-mentioned consequences, it is clear that disclosure and readiness are related. Consequences to an individual who is not ready to disclose may even result in suicide due to unexpected reactions and feelings of disappointment from those persons to whom the individual disclosed. In the past, the individual would be denied financial access by financial institutions and creditors and medical aid cover resulting in more financial burdens; others lost properties and businesses. However, this has changed because of both legislation protecting human rights and also HIV activism; hence there are positive consequences to disclosure (Greeff et al., 2008:316; Mbonu et al., 2009:98; Datta & Njuguna, 2008:95; Goudge et al., 2009:75).

### **2.7.3.2 Positive consequences of disclosure**

When a person has disclosed his/her HIV status and has become part of a support group, participation in such a support group encourages information and sharing, thus resulting in emotional release and psychological wellbeing. The individual may also experience a sense of self-understanding, healing and authenticity in relationships with others. Furthermore, disclosure may enhance a sense of accomplishment and pride, empowerment and sense of purpose. PLWHA who are living openly and positively with their status mention that disclosure made them feel that the burden of secrecy was off their shoulders, and eased rumours and gossip. Another positive consequence of disclosure, for instance, is that disclosure opened an opportunity to educate others and so protect them against contracting HIV. In the workplace, disclosure can promote acceptance of people living with HIV and limit and or eradicate the stigma associated with HIV. Disclosure can lead to increased social support and can mitigate the negative effects of stress. These individuals who have disclosed their HIV status can gain the capacity to reduce stress, change lifestyle and behaviour patterns and thus prolong their

lives. Disclosure of HIV status can also unite families, and give significant others an opportunity to support those who have tested HIV positive. It is also an opportunity to reprioritise one's life (Greeff et al., 2008:316).

#### **2.7.4 HIV status disclosure in the workplace**

There is no doubt that HIV and AIDS have a devastating effect on the workplace, as discussed in section 2.6 of this chapter. Research has mostly been done on the economic impact of HIV on the workplace and how the workplace responds to this impact (Barnett & Whiteside, 2002:245, 247; Dickinson, 2004:42, 79). However, not much research has been done on the impact of disclosure on the workplace. Companies and business are only encouraged to disclose their HIV and AIDS status in terms of financial impact, and the programmes that are in place in dealing with HIV and AIDS in the workplace. Not much research has been done on individual status disclosure (Davies et al., 2002:40).

According to Fesko (2001:2) five factors can motivate an individual to disclose his/her HIV status in the workplace. These factors are:

- the severity of the individual's illness;
- the belief on how much co-workers already know about the individual's HIV status;
- how educated people feel about HIV in the workplace;
- how supportive the work environment is; and
- the anticipated negative consequences

However, Fesko (2001:2) further states that HIV status disclosure is a double-edged sword because the following factors may prevent an individual from disclosing in the workplace:

- fear of discrimination;
- harassment;
- anxiety about losing health benefits; and
- fear of losing advancement opportunities in the workplace.

At the same time, HIV disclosure may create opportunities for medical and social support, which can be critical in reducing the stigma and stress related to illness. Although, if an individual disclosed under pressure, this may lead to extra stress as a result of stigmatisation, discrimination and disruption of personal relationships (Fesko, 2001:2; Greeff et al., 2008:314). Workplace HIV status disclosure can thus be regarded a form of public disclosure. The ripple effect can be endless, whereby the affected individual can lose control of further disclosure without consent (Viljoen, 2005:66).

Based on the information above, there is evidence of the effects of HIV status disclosure on an individual in general, but there has not been much research done on the experiences of individuals who tested HIV positive after the disclosure of their HIV status in the workplace (Greeff et al., 2008:311; Kalichman & Simbayi, 2009:92). It is this gap that prompted this study in order to understand the experiences of individuals after they have disclosed their HIV status in the workplace

## **2.8 Summary**

The extent of the effects of HIV and AIDS on Sub-Saharan Africa, South Africa, on business and government is evident. Although much has been done, the risk of infection is still extremely high with debilitating consequences to both the individual and the workplace. Stigma and discrimination and other social constructs of HIV and AIDS play and will still play a role in the disclosure of the HIV status of the individual. However, understanding disclosure as a phenomenon will pave the way to curbing the spread of HIV and to the design of effective strategies of response (Greeff et al., 2008:311; Fesko, 2001: 2; Davies et al., 2002:25).



## CHAPTER THREE

### RESEARCH METHODOLOGY, EMPIRICAL RESEARCH FINDINGS AND INTERPRETATION

#### 3.1 Introduction

The literature clearly reflects the impact of HIV on the individual, family and the workplace. The relative success in establishing and maintaining a social life was linked to views about the disclosure of HIV status. Some people manage to sustain a full social life despite their HIV status, while others feel that they have to protect themselves and their families by keeping their HIV status a secret (Doyal & Anderson, sa:98). However, Greeff, Phetlhu, Makoe, Dlamini, Holzemer, Naidoo, Kohi, Uys and Chirwa (2008:311) and Kalichman (2009:92) state that most people have disclosed their HIV status to someone, often with mixed results.

Various authors (Doyal & Anderson, sa:100; Maboko & Mavundla, 2006:25; Forsyth et al., 2008:77) assert that very frequently individuals who have tested HIV positive find themselves isolated due to stigma. In the quest to belong, they disclose easily to support groups. It is in support groups where they share similar experiences of living with HIV.

However, in order to provide adequate and efficient support and professional services to employees who have tested HIV positive and have disclosed their HIV status in the workplace, it is important to understand their feelings and experiences. Therefore the goal of this study was the following:

**To explore the experiences of HIV positive employees in the transport sector after they have disclosed their HIV status in the workplace.**

In order to achieve this goal the following objectives were formulated:

- to theoretically conceptualise HIV as a phenomenon with particular emphasis on HIV disclosure in the workplace;

- to explore the experiences of HIV positive employees in the transport sector after they have disclosed their HIV status in the workplace; and
- to draw conclusions based on the research findings, and formulate recommendations to address HIV disclosure problems in the workplace.

Against this background, the following research question guided this study:

**What are the experiences of HIV positive transport sector employees after they have disclosed their HIV status in the workplace?**

## **3.2 Research Methodology**

### **3.2.1 Research approach**

For this study a qualitative research approach was used, as the researcher was seeking to explore the experiences of HIV positive transport sector employees after their disclosure of living with HIV in the workplace. The qualitative research approach was appropriate in this study due to the fact that the researcher sought to understand the feelings and experiences of the participants as they perceived them, as well as the fact that the qualitative approach helped the researcher to enter the world of and form relationships with the participants during the interviews (Delpont & Fouché, 2005:261; Saunders, Lewis & Thornhill, 2003:86).

### **3.2.2 Type of research**

In this study the researcher's focus was on understanding the experiences of HIV positive transport sector employees after they have disclosed their status in the workplace. The most applicable type of research for this study was applied research, because applied research places strong emphasis on application and solving problems in practice (Fouché & De Vos, 2011:95).

### **3.2.3 Research design and methods**

#### **3.2.3.1 Research design**

Leedy and Ormrod (2005:139) regard phenomenological study as a study that attempts to understand people's perceptions, perspectives and understanding of a particular situation. These authors further mention that a phenomenological study tries to answer the question: "what is it like to experience such and such?" Struwig and Stead (2004: 15) further elaborate that phenomenological studies map out the different ways in which people experience, conceptualise, perceive or understand aspects of their world. The phenomenological design used in this study was thus applicable because the researcher wanted to understand the experiences of HIV positive employees in the transport sector after they have disclosed their HIV status in the workplace.

#### **3.2.3.2 Population, sample and sampling method**

According to Saunders et al. (2003:151), population is a set of cases from which a sample is taken. In this study the population was all the transport sector employees who are living with HIV in Organisation Alpha and who have disclosed their status in the workplace. In total the population in this study were 85 employees in the transport sector who are living with HIV and have disclosed their HIV status in the workplace within the following branches of organisation Alpha:

- Pretoria
- Johannesburg
- Menlyn
- Cape Town
- East London
- Durban

Strydom (2005:193) defines a sample as any small portion of the population as the representation of a population under study and as such is considered to be representative. By using a combination of stratified and systematic sampling, three

participants from each branch (stratum) of the six branches of organisation Alpha were selected to form part of the sample. Thus altogether 18 participants were selected who were considered to be representative of the population. At the end only 15 participants formed part of the sample due to the unavailability of three participants in one branch which implies that the researcher has selected the sample from five branches instead of six branches.

Through stratified sampling the researcher ensured that all the different segments of the population at different branches of Organisation Alpha acquired significant representation in the sample. From a list of participants at each branch (stratum) the researcher systematically selected every fifth employee who was HIV positive and who had disclosed his/her HIV status in the workplace (Strydom, 2005: 200).

### **3.2.3.3 Data collection method**

For the purpose of this study, the researcher used in-depth interviews to gather data from the participants. According to Leedy and Ormrod (2005:139), an in-depth interview is often generally an unstructured one in which the researcher and participant work together to “arrive at the heart of the matter”. These authors further state that

“The researcher listens closely as participants describe their everyday experiences related to the phenomenon and is alert to subtle yet meaningful cues in participants’ expressions.”

In support of this view, Greeff (2011:348) notes that in-depth interviews are referred to as a conversation with a purpose. The purpose of in-depth interviews is not to obtain answers to questions, but it is an interest in understanding the interest of other people and the meaning they make out of that interest. Therefore in-depth interviews were an appropriate data collection method for this study.

The researcher excluded any demographical data that could lead to association or identification of the participants, based on ethical reasons, because HIV has ethical and human rights implications. The significance of using in-depth interviews in this study

was because HIV is a very sensitive and personal issue, and it was valuable to the researcher to allow the participants to describe their experiences from their point of view. Thus the one central question put to all participants was: **How would you describe your daily experience of living with HIV after disclosure in the workplace?**

The in-depth interview gave the participants an opportunity to describe their own experiences, feelings and views on the phenomenon of HIV and AIDS and most specifically their experiences after the disclosure of their HIV status in the workplace. It also made it possible for the researcher to probe on certain statements, clarify and simplify questions and statements made by participants. Although it was an in-depth unstructured question which was asked, possible follow-up questions were prepared in advance based on the literature review. Participants were able to take their own time to comprehend and take time to respond to follow-up questions without feeling pressured by a deadline to finish. With the permission of the participants to record the interviews for data analysis purposes, a digital voice recorder was used to tape record the interviews.

After each interview, the researcher played back the recorded interview in order to verify the accuracy of the interviews.

#### **3.2.3.4 Data analysis**

De Vos (2005:333) asserts that data analysis in qualitative studies is a process of bringing order, structure and meaning to the mass of data collected both on-site and off-site and at a final stage a report is written. It is further stated that data analysis in qualitative studies is a search for general statements about relationships among categories of data.

Therefore in this study the researcher, after collecting the data, has analysed the information using Creswell's model of data analysis and interpretation as described by De Vos (2005:334-339).

The researcher met with the participants at the venues as scheduled and collected the data using a voice recorder and written notes. The recorded interviews were listened to carefully and repeatedly, transcribed into text format and were then analysed manually. After the researcher was satisfied and had made sense of their entire responses, the responses were broken down into categories. The researcher identified themes and sub-themes according to the trends and relevance of information.

### **3.3 Trustworthiness of the research findings**

In this study the researcher conducted in-depth interviews with employees who are permanently employed in Organisation Alpha, who are living with HIV and have disclosed their status in the workplace. The list of participants was checked and compared with the Human Resources records for credibility. A digital voice recorder was used, recorded interviews were played back to the participants, then transcribed by an expert and stored on compact discs which can be made available should a need arise. The researcher is passionate about the study and has worked in the field of HIV and AIDS for a long time, therefore it was important for her to utilise strategies that would ensure trustworthiness of the findings. A number of strategies were applied in this study to establish trustworthiness of the findings and these are described below.

- Member checking: The researcher ensured that the findings emerge solely of the research participants with no biases, motivations and researcher's perceptions by applying member checking whereby the recorded interviews were played back to the participants immediately after the interviews. Furthermore, the transcribed interviews were given to the participants to ensure that it was the participants' experiences that have been transcribed not the researcher's interpretation and perceptions (Lietz, Langer & Furman, 2006:453).
- Reflexivity: According to Lietz et al. (2006:449), identifying who the researcher is and being explicit about his/her perceptions is an essential part of reflexivity. In this study, it was crucial for the researcher to acknowledge her own values and

socio-cultural position with regard to the topic of HIV status disclosure. Hence, the researcher probed, asked follow-up questions and reconstructed some questions for clarity from the participants. This strategy was applied to sensitise the researcher to any threats of trustworthiness while leading to the identification of the researcher's socio-cultural perceptions. Reflexivity was also applied through constant meeting and interaction with the senior researcher for extensive dialog on the process of data analysis and interpretation.

- Peer debriefing: Peer debriefing is crucial in qualitative studies. This happens when the researcher meets and talks with a researcher who is outside the project but has expertise in the process of research and the topic to minimise the effects of reactivity and bias (Lietz et al. 2006:451) In this study, the researcher after completing the analysis, met with a senior researcher for peer debriefing. In these peer debriefing conversations, some consistencies and differences in interpretations of the data were identified.
- Audit trail: Lietz et al. (2006:449) define audit trail as the process during data analysis where the steps to be taken are clearly described to ensure trustworthiness of the research findings. In this study, the researcher applied the audit trail by providing the participants with consent form to be signed. It is in the consent form where the process of the reach study and data analysis was described to the participants.

### **3.4 Empirical research findings**

As indicated earlier, this chapter presents analyses and interprets the empirical findings. Data were collected through in-depth interviews with 15 participants who are living with HIV and who have disclosed their HIV status in Organisation Alpha. In this study, the researcher has analysed the data using text analysis according to Creswell's model (in De Vos, 2005:333) with the aim of bringing order, structure and meaning to the mass of collected data.

The recorded voice data have been transcribed and the researcher read through all the transcripts repeatedly, following a coding system. The data were categorised into themes and sub-themes, interpreted and verified with literature. The findings are presented into two sections as follows:

**Section 1:** A biographical profile of the research participants.

**Section 2:** A description of the themes and sub-themes that emerged from the process of data analysis. Each theme and sub-theme will be discussed according to a summary of findings, quotations to verify findings and an integration of the literature.

### **3.4.1 Section 1: Biographical profile of participants**

The research participants were profiled according to the following variables: gender, age, marital status, race, home language, highest level of education successfully completed, current occupational level, whether the individual has started on antiretroviral treatment or not, the person disclosed to and the period after disclosure.

The biographical profile of the sample of 15 participants is presented below.

#### **3.4.1.1 Gender**

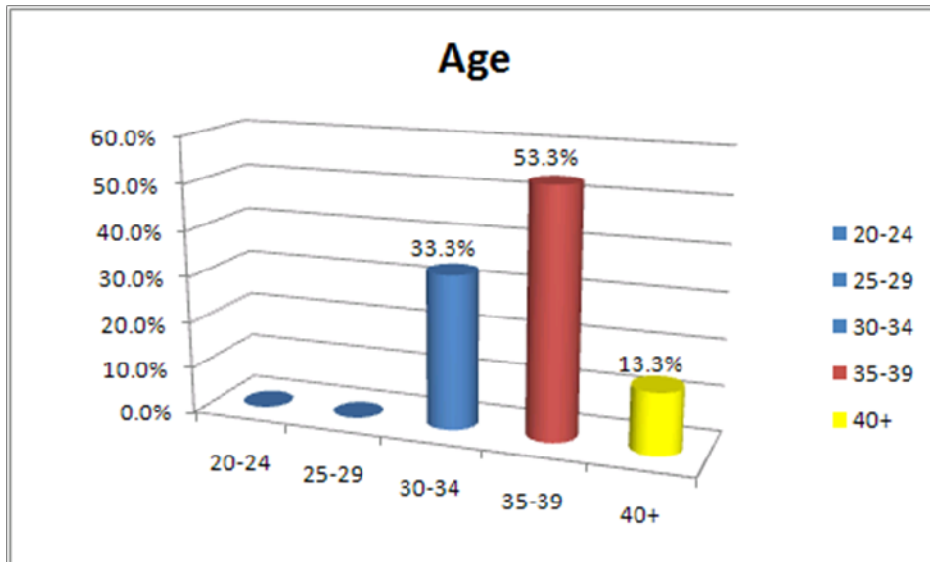
In this study the majority of participants (86%) were females, while 14% were males bringing the total to 15 participants. The majority of women in this study correlate with statistics which refer to the fact that more women live with HIV and AIDS than men (AIDS Epidemic Update, 2009:11; ICAS, 2009).

Women are regarded as the group who are most vulnerable to HIV infection due to their assumed lower social status and gender inequality in many societies (Leclerc-Madlala, 2003:na; Simbayi, Charveau & Shisana, 2004:615). The researcher is further of the opinion that women also seem more open about issues than men. It is therefore not surprising that more women than men have disclosed their HIV status in the workplace.



### 3.4.1.2 Age of the participants

Figure 3.1 reflects the age distribution of the participants.

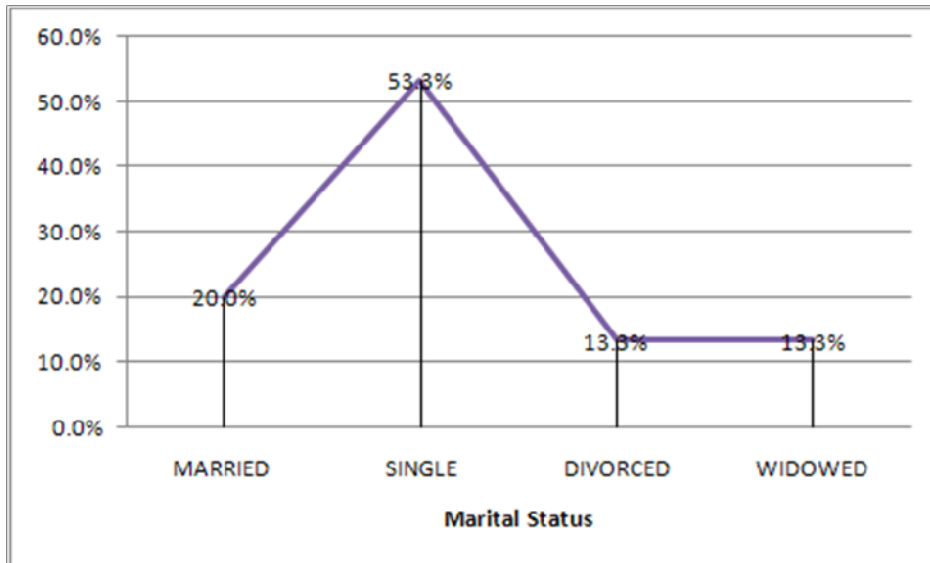


**Figure 3.1: Age distribution of participants**

In this study the majority of participants (53.3%) fell within the age group of 35-39 years, while 33.3% fell within the age group of 30-34 years and 13.3% within the ages of 40 years and above. There were no participants in the ages 20-29. The findings in this study correlate with the findings in a number of research studies on the age distribution of HIV and AIDS (ILO, 2006:10; Rehle et al., 2007:487; Motepe, 2005:56).

### 3.4.1.3 The marital status of the participants

Figure 3.2 below highlights the marital status of the participants.



**Figure 3.2: Marital status of participants**

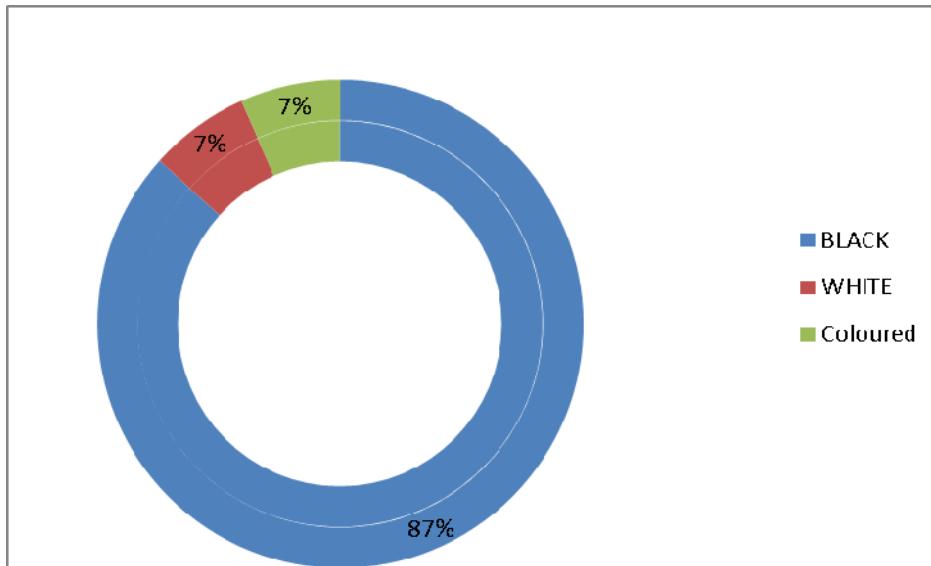
The findings reflect that the majority of participants (53.3%) were single while 20% were married, 13.3% were divorced and 13.3% were widowed.

In terms of the phenomenon of HIV disclosure, considering the lower percentages amongst participants who were married, divorced and widowed, the researcher is of the opinion that it is possibly more difficult to disclose when married, as there will be the assumption that the partner is infected as well. On the other hand, while divorced or widowed the individual might be protecting the significant others. In this regard, Vosloo (1997: na) has mentioned the following:

“You also need to consult with your partner when it comes to disclosure because it is not only you who is subjected to this discrimination but also your family”.

#### **3.4.1.4 Racial distribution of participants**

Figure 3.3 indicates the racial distribution of participants.

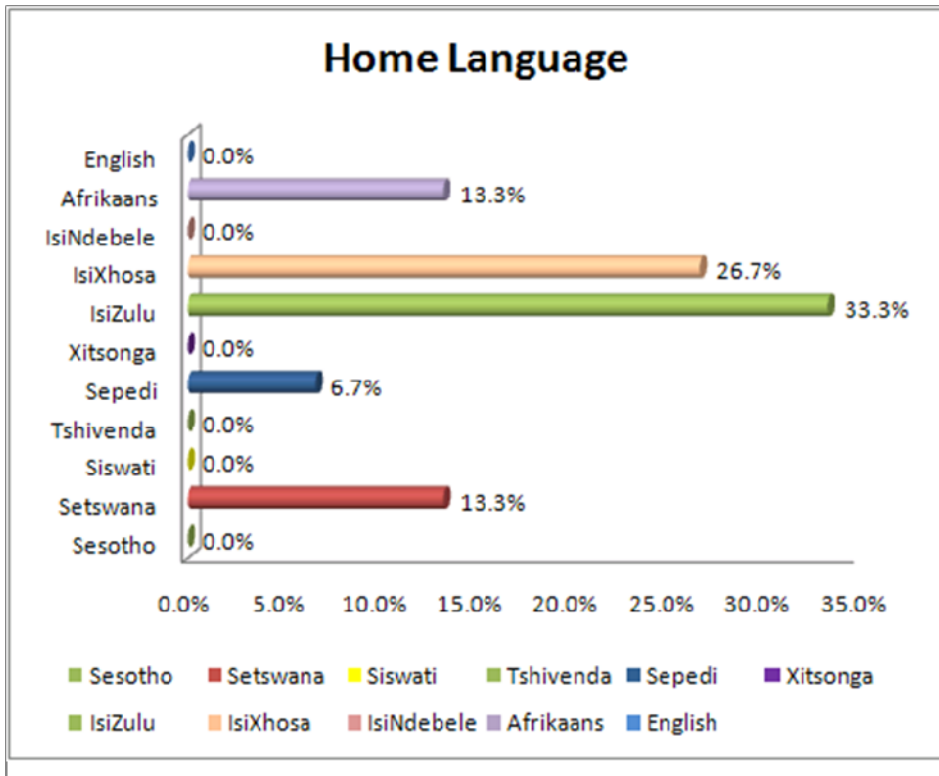


**Figure 3.3: Racial distribution of participants**

From Figure 3.3, it is clear that the majority of participants (87%) were black, while 7% were white and 7 % were coloured. The racial distribution in this study is representative of the population diversity in Organization Alpha. It also correlates with statistics that there is scientific evidence that black people represent the majority of HIV infected individuals (Leclerc-Madlala, 2003; Simbayi, Charveau, Shisana, 2004:615; Goudge et al., 2009:100).

#### **3.4.1.5 Home language of the participants**

Figure 3.4 reflects the home language spoken by the participants.

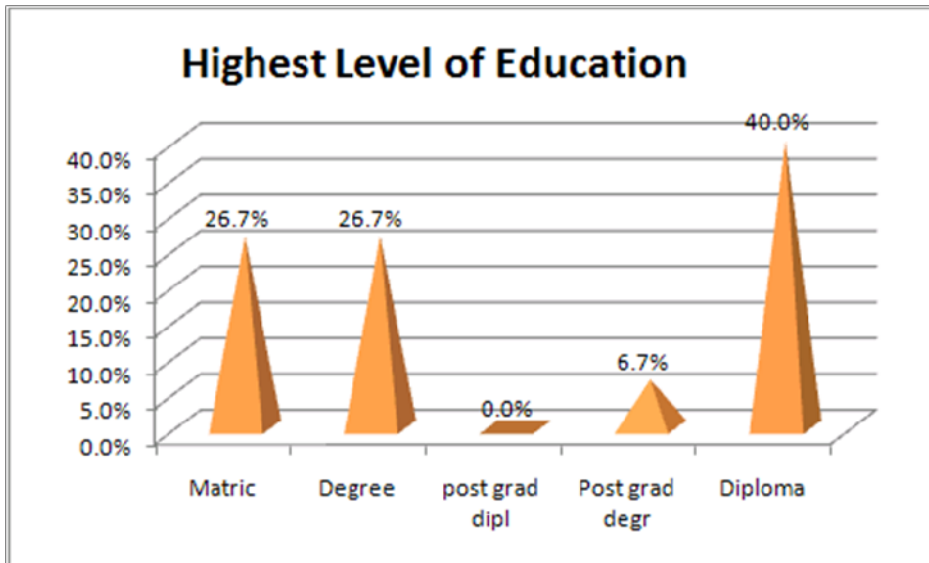


**Figure 3.4: Home language distribution of the participants**

In this study 33.3% of participants were isiZulu speaking, 26.7% isiXhosa, 13.3% Setswana, and 13.3% Afrikaans, while 6.7% were Sepedi speaking. In this study, the home language distribution does not represent any geographic or regional distribution of HIV infections but rather the language spoken by individuals who have disclosed their HIV status and were sampled (Visser & Mundell, 2008:66).

### **3.4.1.6 Highest level of education successfully completed by participants**

Figure 3.5 displays the highest level of education successfully completed by participants.

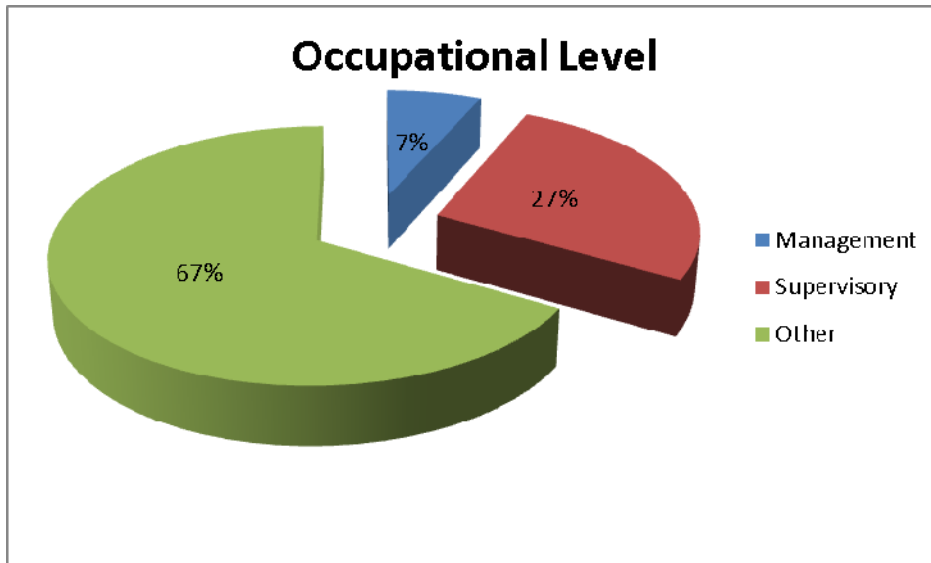


**Figure 3.5: Highest level of education successfully completed by participants**

Figure 3.5 above reflects the highest level of education successfully completed by participants. It is interesting to note that the majority of participants had a diploma (40%), while 26.7% had a degree, 6.7% had a post graduate qualification, and only 26.7% of participants had a matriculation certificate. Figures clearly indicate that the tide has turned; HIV does not only affect people with low socio-economic status but educated people as well (Datta & Njuguna, 2008:95). Based on these findings it is clear that Organisation Alpha is a skill intensive organisation with employees who have a high level of education.

### **3.4.1.7 Occupational levels of participants**

Figure 3.6 reflects the distribution by occupational levels of the participants.

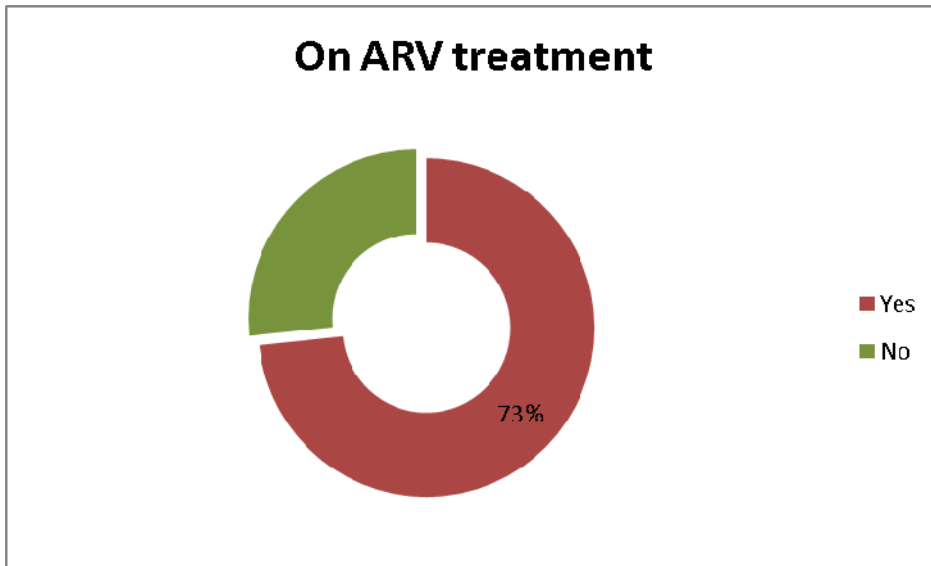


**Figure 3.6: Distribution by occupational levels of the participants**

It is interesting to note that only 7% of participants who disclosed their HIV status belonged to management, while 27% were from the supervisory level and 67% from other categories. The findings are representative of the population in Organisation Alpha. The majority of employees are below the supervisory levels and probably more open about their status than management.

#### **3.4.1.8 Involvement of participants in antiretroviral treatment (ARV)**

Figure 3.7 displays participants taking antiretroviral treatment (ARV).

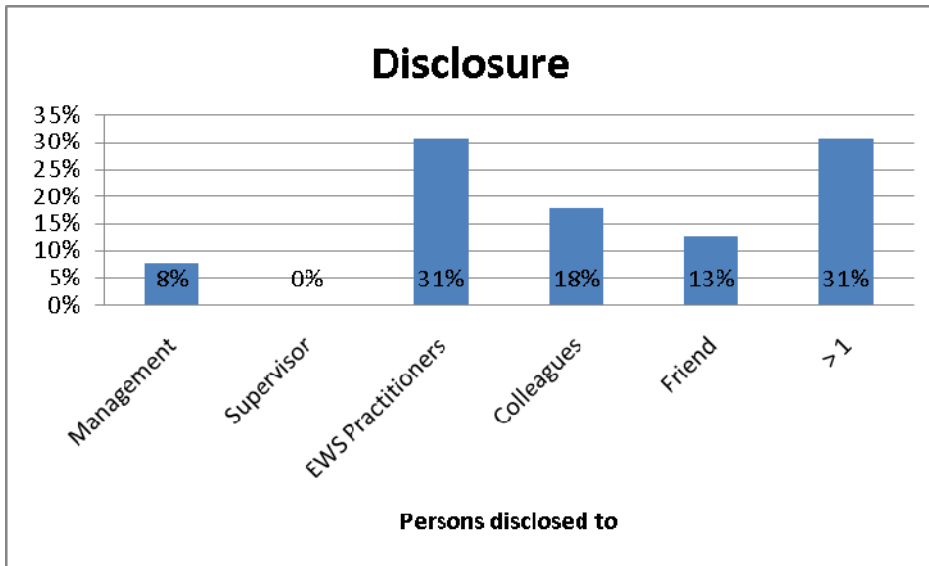


**Figure 3.7: Participants taking antiretroviral treatment (ARV)**

Figure 3.7 shows that 73% of the participants have started with antiretroviral treatment (ARV) already, while 27% are not on treatment. Although the taking of ARVs was not a variable to be measured in this study, it was imperative to note this variable as HIV has an impact on both individuals and the workplace. It is essential to understand how individuals are dealing with HIV, and what contributes to their remaining productivity in the workplace and how the taking of ARV will influence disclosure of HIV status and productivity. Therefore taking treatment was identified as one of the variables of note. According to the literature, the decline in AIDS related deaths between 2001 and 2008 is attributed to the effects of treatment which prolong the life of the infected individual (Poku & Whiteside, 2006:254; Versteeg & Murray, 2008:84).

#### **3.4.1.9 People to whom participants disclosed their HIV status in the workplace**

Figure 3.8 highlights people to whom participants disclosed their HIV status in the workplace.



**Figure 3.8: People to whom participants disclosed their HIV status in the workplace**

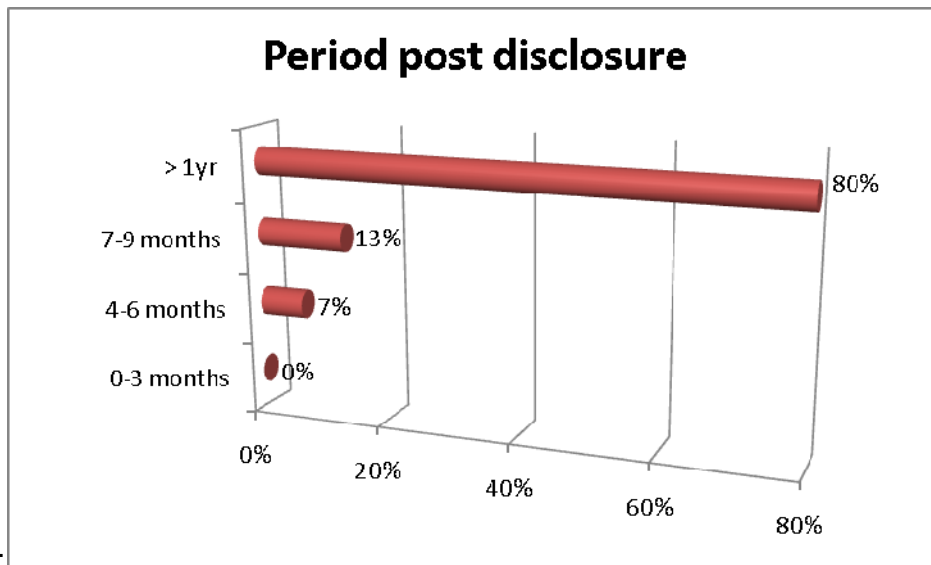
Figure 3.8 above reflects those people to whom participants disclosed their HIV status in the workplace. It is encouraging to note that the majority of participants (31%) disclosed to Employee Wellness Practitioners, as these practitioners possess the skills and professional knowledge to deal with HIV in the workplace. However it is interesting to note that a substantial number of employees preferred to disclose to colleagues (18%) rather than to their managers (8%). Managers are the ones who deal with the day to day performance of employees. It is also significant to observe that 31% of participants disclosed to more than one person in the workplace.

It is however important to remember that it is clearly stated in the literature that in voluntary disclosure, the Person Living with HIV/AIDS (PLWHA) maintains control over the choice to disclose, to whom he/she chooses to disclose and whether he/she should fully or partially disclose (Visser & Mundell, 2008:66; Greeff et al., 2008:313).

#### **3.4.1.10 The period since the participants disclosed their status**

Figure 3.9 reflects the period after disclosure of HIV status.





**Figure 3.9: Period after disclosure of HIV status**

Figure 3.9 above reflects how long ago they have disclosed their status in the workplace. The majority of participants (80%) mentioned that it was more than a year since they have disclosed their status, while 13% indicated that it was between seven and nine months since they have disclosed, and only 7% was between four and six months since they disclosed their HIV status in the workplace.

Since there were participants who had disclosed more than a year ago, it clearly indicated that these individuals have been living with HIV for a significant period and had probably made a conscious decision to disclose, had accepted their individual HIV status and shared valuable information regarding their experience of living with HIV in the workplace. The researcher is of the opinion that HIV status disclosure is a process and an individual should disclose only when that individual is ready to deal with whatever reaction he/she will receive from those he/she chooses to disclose to.

### **3.4.2 Section 2: Qualitative information according to themes and sub-themes**

In this section, the qualitative data findings are discussed according to themes and sub-themes. Table 3.1 below displays a summary of the identified themes and sub-

themes in this study.

**Table 3.1: Summary of the identified themes and sub-themes**

No	Theme	Sub-themes
1	Support systems in the workplace	1.1 Management 1.2 Colleagues 1.3 Employee Wellness Practitioners
2	Stigmatisation after HIV status disclosure in the workplace	
3	Level of HIV knowledge in the workplace	3.1 Management 3.2 Colleagues
4	Reasons for disclosure of HIV status in the workplace	4.1.Ill Health 4.2.Absenteeism and poor performance
5	Benefits after HIV disclosure	
6	Emotional experiences	6.1 Relief 6.2 Anger and blame 6.3 Fear of rejection 6.4 Fear of imminent death
7	Challenges of being on ARV treatment	7.1 Physical challenges 7.2 Lack of privacy

Each theme will be discussed according to the following structure:

- Theme;

- sub-theme;
- summary of findings;
- quotations to verify the findings; and
- integration of literature.

### **3.4.2.1 Theme 1: Support systems in the workplace**

The majority of the participants highlighted that they had received support in the workplace after they had disclosed their HIV status from Employee Wellness Practitioners, colleagues and management. However, some participants felt that they were not supported by their managers after they had disclosed their status. Three sub-themes were thus identified namely:

- support by management;
- support by colleagues, and
- support by Employee Wellness Practitioners.

#### **Sub-theme 1.1: Support by Management**

Although managers are in the front line in dealing with employees in their daily performance and productive lives, only a few participants felt confident enough to disclose their HIV status to their managers and as such reported support from them. Only a few participants who disclosed their HIV status to management were confident that management by the virtue of their occupational level as managers in the workplace would keep the information disclosed to them confidential. A number of participants mentioned that managers had been supportive in terms of giving time off for the individual to go for treatment. The following quotations verify the experiences of participants:

- *“The manager and my supervisor were very helpful. They were encouraging me to proceed with the treatment.”*
- *“I disclosed to my manager and she was very supportive, as a person who has knowledge on HIV issues. She makes sure that I take my treatment, encourages*

*me to lead a healthy lifestyle. Actually she monitors me and advises me. Whenever I need advice, she is there for me.”*

However, the majority of participants felt that they were not supported by their managers; instead they were disregarded and whether or not they were managing was not taken into account, especially during the symptomatology times. One of the participants even mentioned that managers at times joked about her physical appearance and the fact that she was at times sick, particularly during the winter season. The following quotations verify the experiences of participants:

- *“During winter time when you get sick and things like that, it’s problematic. It feels like you’ve got to force yourself to work, because then it looks like people will start saying when are you going to work?”*
- *“He (my boss) will even make a joke about my disproportional body.”* (Meaning that her upper body is bigger than her lower body)

In view of the above statements, it is clear that the participants perceived and experienced the level of support by managers differently. The diagnosis of a severe life-threatening condition such as HIV is a highly distressing event for an individual, with initial emotional responses including shock, denial, anxiety, sadness, physical illnesses and despair which may lead to an individual disclosing his/her HIV status to the manager for support (Padayachee, 2005: 36; Greeff et al., 2008: 12; Maboko & Mavundla, 2006: 28). Although the literature does not clearly confirm or reject the participants’ experience, ILO (2003:2) provides the following guidelines and principles for employers with regard to providing support for employees who are living with HIV and AIDS in the workplace:

- Listen to employees. Negotiate care and support with them and do not dictate to them.
- Ensure that care and support do not draw attention to the individual who has disclosed his/her HIV status.
- Ensure that the support given is responsive to the individual employee’s need.

- It is almost certain that all HIV positive employees will at some point need some appropriate changes to their work duties and working conditions in order to keep working productively. Care and support packages may depend on the individual HIV positive employee and the needs of the organisation.

This is confirmed by Walch, Lezama and Giddie (2005:58) when these authors mention the following:

“Workplace policies set standards of behaviour for both management and employees of organisations and provide a guide for decision making on day-to-day business affairs. Therefore workplace HIV policies are the significant predictor of the breadth and quality of workplace HIV education and prevention programs.”

Walch et al. (2005:58) further assert that the available data indicates that more and more people are living longer and enjoying more active and productive lives with HIV in the workplace. The researcher is of the opinion that, although there is no specific reference in the literature to management support in the workplace for an individual who has tested HIV positive and has disclosed his/her HIV status in the workplace, the manager represents the employer. Therefore the guidelines and principles of support and care for HIV employees are applicable to management support. It would benefit the business if managers and employees were informed on how to manage HIV and AIDS in the workplace. Furthermore, managers should know their organisation’s policy on HIV, they should seek to be more informed about the legal implications in the workplace, and they should adequately accommodate employees living with HIV after they have disclosed in the workplace.

### **Sub-theme 1.2: Support by colleagues**

As indicated in Figure 3.8, 18% of the participants disclosed to colleagues, and all of them felt that they were receiving the support they needed. However, one of the participants mentioned that upon her HIV status disclosure some colleagues wanted to

take over her life instead of just being there for her when she needed them. These experiences of support are confirmed by the following quotations:

- *“When I disclosed to my colleagues, they were shocked but they are very supportive.”*
- *“My colleague was very, very supportive. The unfortunate part she was not alone, she was with somebody else and they are both my colleagues. This other colleague said she wanted to suggest alternative medication and like (you know) try this and that and things like that. It becomes difficult. I think that despite my HIV status I am still a human being, I am still capable of making my own decisions.”*
- *“We are sharing everything as we used to before I disclosed to them; we are sharing our food, our spoons, so for me it’s just like I’m a normal person; there’s nothing wrong with me.”*

It is interesting to note that when individuals have confidentially disclosed their status to their colleagues, they receive the support as described in the above statements. Colleagues can play a major role in workplace support and therefore it is important that organisations should invest in this type of support by offering training on HIV and AIDS issues in the workplace. Fortunately it seems as if the majority of workplaces in South Africa, in response to the scourge of HIV, have established Peer Educator Programmes to assist in mitigating the impact of HIV and AIDS in the workplace (Dickinson, 2006:6).

Fesko (2001:236) mentions that some asymptomatic HIV positive individuals decide to disclose their HIV status as a coping mechanism to regain control over their lives. Therefore it is the researcher’s opinion that although an employee has been diagnosed HIV positive, that person can still make his/her own decision on how to run his/her life and that needs to be respected by colleagues. However, the researcher is of the opinion that, even while colleagues are providing support to their HIV positive colleague, the sense of individuality should be respected. Admittedly there is not much in the literature that relates to post HIV status disclosure in the workplace.

### **Sub-theme 1.3: Support by Employee Wellness Practitioner (EWP)**

The majority of participants disclosed their HIV status to the EWP. Almost all participants who had disclosed to the EWP experienced that the service rendered in the workplace gave them hope to continue living. They perceived the support to be valuable and to extend beyond the call of duty with the involvement in their personal and family lives when it was necessary. The majority of participants had confidence in the practitioners that their information was safe. All participants felt that they received a high level of support, and care and they described the support they were given by the EW practitioners as follows:

- *“Oh my gosh, she was so supportive, I couldn’t believe it, she was so supportive.”*
- *“I trusted her, I know that EWP will never; never tell anybody; she was supportive.”*
- *“I feel more comfortable to talk to wellness as I know they understand my situation. She is supportive I can call at any time. She has given me a lot of support and told me this is not the end of the world, she is like a mother to me, she educates and gives me as much information as possible.”*
- *“I was hospitalised for about three months, she visited me in hospital and supported me until I was discharged. Even now she continues supporting me.”*

These findings are confirmed by Arns, Martin and Chernoff (2004:378) that, amongst other reasons, people who are living with HIV return to work for emotional and psychological benefits, such as enhanced self-esteem and feelings of usefulness as well as the social and physical activity that entering the workplace can facilitate.

In support of the above authors, the Standards for Employee Assistance Programmes (EAP) (2005:7) clearly describe the support function of an Employee Wellness Practitioners. EAP is defined as a workplace programme designed to assist in the identification and resolution of productivity problems associated with employees impaired by personal concerns, including but not limited to, health, marital, family, financial, alcohol, drug, legal, emotional stress or other personal concerns which may adversely affect employee job performance. Therefore it is quite inspiring to hear that Organisation Alpha where the study has been conducted has a supportive EAP with

Employee Wellness Practitioner who can confidentially and promptly identify, assess and assist employees who are living with HIV and AIDS.

### **3.4.2.2 Theme 2: Experiences of stigmatisation in the workplace**

A substantial number of participants experience stigmatisation at some point and time after they have disclosed their HIV status in the workplace. Although the stigmatisation was thought to be subtle, they stated that there were some unpleasant remarks made by both managers and colleagues regarding their physical appearance, their work attendance and their ability to do the work other employees who are HIV negative can do. Some experienced that other colleagues spoke negatively about them and as a result they had decided to isolate themselves and avoid attending any organisational social activities.

A number of participants stated that at times they felt like shying away from people as they feared the discomfort of being asked questions based on their physical appearance, questions that might necessitate disclosure to unintended people. Also what came out clearly was that, due to their physical appearance, it seemed that people could see that they were HIV positive and therefore would reject them. The following quotations verify the experiences of stigmatisation:

- *“I got few people I communicate with since I was diagnosed with HIV and have disclosed my HIV status in the workplace. It looks like everybody is gossiping about me.”*
- *“I do not attend end of the year functions, the games or any social function in the organisation because it sometimes hurts when people you know say bad things about you.”*
- *“I would say sometimes you wish the world would swallow you because every corner it’s a story about you. I do not understand that a person can have joy about somebody who is sick. I feel I can resign.”*

These findings are confirmed by findings in a study conducted by Samson, Lavigne and Macpherson (2009:1427) that the secrecy of living with HIV makes those who live with



HIV feel as though they have lost their dignity and intrinsic self-worth. These feelings of rejection are a source of lingering moral suffering which adds to the torment of living with a potentially fatal disease, and feelings of loneliness and sometimes of having been abandoned.

It is clear that although HIV has been in existence for more than three decades, stigma was still being experienced by those who were HIV positive and had disclosed their status. Kalichman and Simbayi (2007) and Padayachee (2005:34) mention that stigma is a social construct which has a significant impact on the life experiences of those individuals who are infected or affected by HIV and AIDS leading to overly discriminatory behaviours like gossip, and thus contributing to non-HIV status disclosure in most workplaces. It is further believed that stigma can be associated with lack of knowledge regarding how HIV is transmitted and the basic facts about HIV in general, hence some participants mentioned lack of knowledge as an issue with regard to HIV status disclosure (Doyal & Anderson, sa:97).

### **3.4.2.3 Theme 3: Level of HIV knowledge in the workplace**

The decision about disclosing a person's HIV status in the workplace can be linked to the level of knowledge regarding HIV in the workplace. All participants acknowledged that there were risks or challenges associated with not disclosing their HIV status in the workplace. They stated that some of those risks could be the level of knowledge and readiness of the workplace to embrace employees who had tested HIV positive. Although the majority of participants disclosed to management and EW Practitioners, they stated that it was a passive voluntary decision. Greeff et al. (2008: 313) define passive voluntary disclosure as when an individual has no other choice but to disclose. This type of disclosure is common in the workplace. These participants do not regret disclosing, but feel that it was the best thing to do.

However, a concern was that although the participants had disclosed their HIV status in the workplace and they received support, only few of them know the contents of the HIV workplace policy. Two participants did not even know that there was a workplace HIV

policy. A third participant had reported a lack of HIV knowledge by management and colleagues, while some felt that there was enough HIV knowledge in the workplace, but their experience was that some employees are deliberately in denial of the existence of HIV and AIDS. Two sub-themes were identified namely (1) management's level of HIV knowledge, and (ii) colleagues' level of HIV knowledge.

### **Sub-theme 3 1: Management's level of HIV knowledge.**

Some of the participants linked their negative experiences with regard to the disclosure of their HIV status in the workplace to management's lack of knowledge regarding the basic facts of HIV. Some stated that managers were not skilled in dealing with HIV disclosure in the workplace to the extent that managers would make remarks which were hurtful at times, while others experienced that managers could not deal with the emotional challenges experienced by these participants. The following quotations reflect the experiences of the participants with regards to lack of knowledge by managers:

- *"In the workplace, I think managers have to be made aware that people who live with HIV have mood changes from time to time. They must know that people have health related problems; our performance may go down things like that."*
- *"But my main concern is with managers, the questions they ask around and sometimes they joke about it."*
- *"Management needs to be educated on HIV because the little knowledge they have is destructive."*
- *"I think management needs to be supportive when somebody is sick. I think they also need to get training."*

Confirming the findings, although not specifically the level of knowledge, Walch et al. (2005:60) state that several studies have found that managerial fear of HIV and AIDS is a significant predictor of both the decision for managers to discipline a co-worker who refuses to work with a HIV positive employee and the willingness to disclose confidential medical information about an HIV positive employee, to others. The researcher is of the opinion that although literature is not clear on the issue of managers' level of knowledge

regarding HIV issues, lack of knowledge about basic facts about HIV and AIDS contributes greatly to the fear of HIV infected employees as stated by the above author.

### **Sub-theme 3.2: Colleagues' level of HIV knowledge.**

Although the majority of participants viewed knowledge about HIV in the workplace as enough, a substantial number of participants still felt this knowledge was not adequate. Some felt that the low level of knowledge by colleagues was related to denial of the existence of HIV in the workplace. The quotations below highlight the level of knowledge amongst colleagues:

- *“I can say that they have the knowledge, but it is not enough, maybe they don't have people who guide them about AIDS.”*
- *“The stigma is no longer an issue as it was before, that's what I have discovered, because now people are openly talking about their status even to other colleagues and in a non-formal way during conversations, therefore I think there is enough knowledge.”*
- *“You know sometimes, colleagues the way they talk making comments like ‘that one is about to die’ things like that, then you feel that these people lack knowledge and sometimes it is that little knowledge that is dangerous.”*

In view of the above responses linked to the lack of knowledge about HIV status in the workplace and participants' adverse experiences related to their disclosure of HIV status, it is clear that Organisation Alpha still has a long way to go before all employees can be comfortable about disclosing their HIV status. The researcher is of the opinion that it is due to lack of knowledge that most People Living with HIV experiences stigma in the workplace. The literature suggests that employee characteristics, such as difference in upbringing, value system, knowledge about and experience of HIV, and willingness to learn new information may have an impact on employee receptivity to training and acceptance of HIV information, and the attitude regarding the behavioural transmission of HIV (Walch et al., 2005:67). Smit (2004:23) confirms the above finding by elaborating on the need for the provision of high quality educational programmes for nurses who care for People Living with HIV/AIDS. The author further states that these

programmes will not only result in reducing nurses' negative attitudes towards patients living with HIV, but may contribute to a more positive attitude towards these patients. The researcher is of the opinion that although these findings were from a study done in a hospital setting, the findings are applicable to all workplaces.

#### **3.4.2.4 Theme 4: Reasons for disclosure of HIV status in the workplace**

The majority of participants indicated that they disclosed their HIV status in the workplace because they were very sick and had been admitted to hospital. Others disclosed their status because of their high level of absenteeism, a few had performance related problems and only two participants disclosed their HIV status because they felt they needed to talk to somebody about it. Another two disclosed after a workshop on HIV status disclosure and felt it was time for them to disclose. From these responses, two main sub-themes were identified namely:

- ill health
- absenteeism and poor performance.

##### **Sub-theme 4.1: Ill health**

The majority of participants reported that the main reason for disclosing their HIV status in the workplace was their experiences of ill health which resulted in hospitalisation. All of them suffered from multiple organ failure which resulted in long periods of absence from work. They all reported that the first condition they presented with was Pulmonary Tuberculosis (TB) which led to HIV testing.

Fifty percent of the participants had indicated that when they discovered that they were HIV positive for the first time, already their CD4 count was below 200 and as such they had to start with ARV while 25% started with ARV long after they had been diagnosed. Some made the following comments:

- *“I was constantly sick and even had developed multi-organ failure which made me to disclose in the workplace.”*

- *“Ja what led me to disclose, I was persistently sick. On this particular time of disclosure, I had multi-organ failure and I anticipated death. So I thought it is better if I disclose so that if I die at least they know I had HIV.”*
- *“There are many reasons that made me disclose, one of them was that I was very ill and weak, I was thin and I was in a desperate situation.”*
- *“I had TB and I was admitted to hospital again and again.”*

The participants' experiences of ill health which led to disclosure are confirmed in the literature. HIV is described as a life-threatening condition which an individual may manifest with low grade fever, chronic fatigue, loss of appetite and muscle wasting (Calitz, 2008:51). The author mentions that as the condition progresses to a late stage of AIDS where the body can no longer fight infection and multiple organs are affected, individuals may be hospitalised. These views are supported by a number of authors who also mention that during the stage of AIDS when an individual suffers from debilitating opportunistic conditions, for example disseminated tuberculosis which accounts for approximately 8-10 million of AIDS patients, an individual can be on prolonged sick leave (Barnett & Whiteside, 2002:245, 247; Dickson, 2004:42, 79).

#### **Sub-theme 4.2: Absenteeism and poor performance**

As cited in the above section, the majority of participants disclosed their HIV status in the workplace because they experienced serious health problems. The participants mentioned how their ill health kept them away from work for prolonged periods. The consequence is that when an individual is not at work, the individual cannot perform therefore their performance was negatively affected. They indicated that at times they were not coping emotionally resulting in absenteeism and poor work performance, hence they felt they should disclose their status in the workplace so that it could be understood why they could not meet the set standards of performance. The following quotations verify their experiences:

- *“Sometime you can't even understand your own body, what is happening to me? Should I go to work or not? Sometimes you can't even perform.”*

- *“When I disclosed to my friend, my friend said I should go and disclose to my manager so that he can understand that I have a problem. At that time I could not focus on my work, I was always drowsy, I was not coping.”*
- *“Initially I was always exhausted and my work performance went down and then I was more off sick than being at work.”*

According to the literature, HIV and AIDS related absenteeism in South Africa contributes to 15% of the 37% of absenteeism in the workplace (Dickson, 2004:36). According to Calitz (2005:20), an individual who is living with HIV is three to four times more absent from work than an HIV negative employee. This trend is associated with a number of factors from emotional to physical illnesses. Due to absenteeism, companies lose substantial amounts of money, which affects productivity and the staff morale of those employees who have to take over the work of the sick employee (Dickinson, 2004: 42-79; Bower, 2002:26). The researcher believes that when employees disclose their HIV status, it can assist the workplace to plan and mitigate the effects of absenteeism.

#### **3.4.2.5 Theme 5. Benefits after HIV disclosure in the workplace**

The majority of participants support HIV status disclosure in the workplace. Some mentioned that they experienced different advantages of HIV and AIDS disclosure in the workplace. They highlighted the fact that they experienced the advantage of support and less gossip amongst colleagues. They emphasised the importance of readiness of the person who wishes to disclose. They felt disclosing their HIV status in the workplace was the best thing to do as it relieved them from the burden of secrecy, and emphasised that people should not wait until they are sick before they disclose. Only two participants felt that it is not a good idea to disclose their HIV status in the workplace because they feared rejection and the comments made by colleagues which might hurt. These different experiences are illustrated by the following quotations:

- *“I think that HIV disclosure in the workplace is a useful thing, because in the first place when you are sick and nobody knows that you are having*

*this problem, you continue being absent then it is a problem. If you disclose, the supervisor and the managers may know that this person is sick and therefore support you.”*

- *“Aah, I don’t think... aah, it depends. You know we don’t deal all with the whole HIV and AIDS thing the same way; some people can’t face rejection from work then where do you turn to?”*
- *“Hei I don’t know, I don’t think it’s wise because people who are HIV positive, hei it’s like you must not be part of family or business or what, they discriminate against you.”*
- *“Yes I will encourage people to disclose. I would encourage people to work through their feelings at least to direct them to disclosing. It is hard, it is difficult I know but after you have disclosed you become so light. So I would encourage people to do it before it is too late.”*

The literature confirms the participants’ mixed experiences of benefits and disadvantages linked to the disclosure of their HIV status in the workplace. According to Fesko (2001:236) workplace HIV status disclosure is a double edged sword; on the one hand it may create opportunities for medical and social support which is critical in adjusting to the illness and can be a positive experience to some individuals. On the other hand it may lead to extra stress as the result of stigmatisation, discrimination and disruption of personal relationships.

### **3.4.2.6 Theme 6: Emotional experience after HIV disclosure**

A variety of emotional experiences were voiced by the participants. The most prominent experiences were the following: relief, anger and blame, fear of rejection and fear of imminent death. Each will be described as sub-themes.

#### **Sub theme 6.1: Relief**

The majority of participants experienced a feeling of relief immediately after disclosing their HIV status in the workplace, as if a huge burden had been removed. As such, they all mentioned that they have no regrets about disclosing their status in the workplace.

The following quote verifies the experience of relief the participants felt after they have disclosed their status in the workplace:

- *“After I disclosed to my manager, I felt so relieved as if a huge burden has been taken off my shoulders.”*

This finding is confirmed by a number of authors (Greeff et al., 2008:316; Mbonu et al., 2009:98; Datta & Njuguna, 2008:95; Goudge et al., 2009:75) by stating that when a person has disclosed his/her HIV status, they can be part of support group. As such support groups encourage information sharing, thus resulting in emotional relief and psychological well-being.

### **Sub-theme 6.2: Anger and blame**

Few participants experienced the emotional reaction of anger and blame. Mostly, these feelings were attributed to experiences of betrayal by partners or family members, or due to the loss of loved ones and at times these feelings are projected in the workplace. The experience of anger is reflected in the quote below:

- *“When I was pregnant, I discovered that I was HIV positive, I was very angry to everybody at work, I was angry with the world, I was angry at myself, I was angry at the workplace but I don’t know why, at the time I felt it was everybody’s fault.”*

It is clear that HIV as a life-changing situation is characterised by emotional reactions as demonstrated in these findings. Any life crisis is characterised by stages of anger, where an individual will be angry with himself/herself coupled with blame, wondering what he/she has done to deserve it. He/she also blames loved ones for not protecting him/her or in cases of HIV blaming the person who infected her or him and the world. These are normal stages of grieving (Fan, Conner & Villarreal, 2004:51).

### **Sub-theme 6.3: Fear of rejection**

A number of participants experienced fear of infecting others and thus being rejected. These participants highlighted that if an incident happens in the workplace and they



bleed they might have to disclose their HIV status. To protect others, they decided to isolate themselves and cut themselves off. Although isolating themselves was their own decision, they experienced feelings of rejection and a sense of abandonment. The following quotations confirm the fear of rejection:

- *“If something happens, then which means that you are going to kill all of these people, because there is nothing that they know about you in the workplace, if they know they might reject or be scared of you.”*

In the view of the above findings, it is also clear that the fear of rejection is a reality and it can contribute to a fear of disclosure in the workplace. If individuals do not disclose in the workplace, they deny themselves an opportunity to be supported and will not be able to access treatment. Doyal and Anderson (sa:97) confirm that there is evidence of rejection by families and colleagues in most families and workplaces. However, disclosure of HIV empowers the individual to change his/her life and the perceptions of the society, and can reduce stigma in the workplace. At the same time disclosure in the workplace may create opportunities for medical services and social support (Fesko, 2001:236).

#### **Sub-theme 6.4: Fear of imminent death**

A majority of participants experienced fear of imminent death associated with being diagnosed as HIV positive. A substantial number of participants mentioned that when they disclosed to someone in the workplace, some colleagues assumed that they were dying. This has been a general perception as far as HIV and AIDS is concerned, as it was in the early stages of the disease before the discovery of the ARVs that people were dying within a short space of time after diagnosis. Although some participants reported death in a positive way, it seemed there was a concealed fear of how long one will live with this disease. The following quotations verify the fear of death as experienced by the participants:

- *“I had multiple organ failure at one stage, so I anticipated death, so I thought it is better if I make them aware that I am HIV positive in case I die at least they know what the reason was or what led to my death.”*
- *“I don’t want to die; I want to see my daughter graduating. I would rather take those ARVs, I’m really afraid of death; I have a person who depends on me.”*

The fear of death experienced by the participants may be based upon previous losses either of a partner, relative, colleague or family member. These experiences can be generalised to the fact that previously there were high numbers of deaths due to AIDS related illnesses (AIDS Epidemic Update, 2009:21). Hence there was the myth that testing HIV positive is a death sentence. The researcher is of the opinion that, although the comments may be related to fear of death as experienced by the participants, the reality is that previously AIDS related deaths were alarming. Various studies that were conducted reported high death rates due to AIDS related illness. Between 2001 and 2008, 1.4 million people died due to AIDS related illness. Although the number of people living with HIV is still increasing, deaths related to AIDS seem to stabilise due to the provision of antiretroviral treatment (Poku & Whiteside, 2006:254). Access to ARVs, increase in scientific research around HIV and improved HIV and AIDS management programmes are also stabilising AIDS related deaths HIV infection rates, although they are still unacceptably high (AIDS Epidemic Update, 2010:2).

#### ***3.4.2.7 Theme 7: Challenges of being on ARV treatment after HIV disclosure in the workplace***

The majority (73%) of participants started with antiretroviral treatment. A substantial number of participants mentioned that they experienced different challenges related to taking their antiretroviral treatment in the workplace. According to the findings, the ARVs are supposed to be taken at a particular time which posed challenges in terms of privacy, as these times are during working hours. Other challenges are related to changes in physical appearances and side effects which are so peculiar that one cannot hide them. The main challenges experienced by the participants will be discussed under the following sub-themes:

- physical challenges, and
- lack of privacy

### **Sub-theme 7.1: Physical challenges**

A substantial number of the participants, who have started with antiretroviral treatment after their HIV disclosure mentioned some form of adverse effects and physical changes which caused serious challenges in the workplace. The quotations below indicated the physical challenges the participants experienced:

- *“Now that I am taking the treatment I have picked up so much weight; however, I am glad because now people will think that I am no longer sick.”*
- *“Sometimes you don’t want to wake up, all these side effects. My feet are swollen I can’t walk.”*
- *“Because of the treatment I developed osteoporosis and as such limping and I needed to go and have a hip replacement, the limping you can’t hide it to anybody.”*
- *“I have a problem with ARVs I have side effects, I have a big stomach.”*
- *You see these ARVs, now (nginemicondo) (ethnic) thin wasting of lower legs which results in abnormal thin lower legs.”*

It is no doubt that ARVs have significantly contributed to the reduction of HIV and AIDS related deaths and have thus prolonged life and successfully prevented mother to child transmission (United Nations on HIV/AIDS, 2008:30) However, as reflected by the findings, ARVs have significant side effects that are visible. In support of the findings, Lonergan, Behling, Pfander, Hassanein and Mathews (2000:162) mention the hyperlactemia and hepatic abnormalities which were characterised by an overweight, extended abdomen and gastro-intestinal complaints to a certain regimen of ARVs. In support of the above authors, Montessori, Press, Harris Akagi, and Montaner (2004:170) further assert that ARVs can have a wide range of adverse effects on the human body occurring early in most antiretroviral regimens, which may manifest with gastro-intestinal effects such as bloating, nausea and diarrhoea, headaches, anaemia, fat maldistribution, and peripheral neuropathy.

In view of the above research findings, it is clear that employees infected with HIV do not only struggle with a diagnosis of a life-threatening disease, but they also struggle with the effects of antiretroviral treatment. Certainly, these physical challenges also have a direct impact on the workplace in terms of costs related to the high rate of absenteeism caused by long-term illnesses, indirect costs of decreased productivity due to illnesses, the rise in medical aid tariffs and early retirement due to ill health. The researcher is of the view that the impact of HIV and AIDS can be mitigated by establishing Employee Wellness and Health services thus reducing the costs of HIV and AIDS in the workplace.

### **Sub-theme 7.2: Lack of privacy**

Another challenge of being on ARV treatment as mentioned by a number of participants is a lack of privacy due to the open plan offices of Organisation Alpha. Participants cited that they have to take their antiretroviral treatment at about 08H00 in the morning and 20H00 in the evening. Although the participants had disclosed their HIV status in the workplace, disclosure was not done in full in the workplace but only to some colleagues, managers or Employee Wellness Practitioners. Therefore privacy when taking ARVs at work was one of the greatest challenges mentioned by participants. Some of the statements are quoted below.

- *“This open plan environment is not conducive to people living with chronic conditions. But if it was in a closed office, you could have closed your eyes and the pills could have settled down and you are o.k. Now you have to explain to everybody, you feel like you do not have privacy at all.”*
- *“When I have to change my medication, I have to make a call to my case manager to report the effects; I have to stand up and go to a private place, maybe the smoking area, use my cellular phone to ask whatever questions I have about the new treatment.”*
- *“Even the fact that you have to take treatment every morning and every evening at a specific time, you have to explain.”*

Breuer (2005) confirms the findings about privacy as a challenge by stating that like mental illness HIV and AIDS is a stigmatised disease. He mentions that Multiple Sclerosis HIV and AIDS is an episode of disability which means the bouts of illness or adjustment to medication punctuate periods of stabilised health. Employees who have tested positive need information and coaching on how to manage the workplace so that they can preserve their privacy. Ware, Wyatt and Tugenberg (2006:907) support the above author and mention that poor adherence to ARV was the result of people's fear to disclose their HIV status due to stigma. Most importantly these authors mention an issue of the dilemma facing people living with HIV in that they are with other people at the time they have to take their treatment which results in compromised adherence.

It is clear from the findings that privacy for people living with HIV in the workplace, particularly individuals who are on treatment, may become a barrier to disclosure their HIV status in the workplace. Lack of privacy may be the issue which may perpetuate stigma and gossip around employees who are living with HIV. It is therefore of great concern, and it seems that not much research is being done in this regard.

### **3.5 Summary**

The goal of this study was to understand the experiences of employees in the transport sector who are living with HIV and had disclosed their HIV status in the workplace. From the qualitative data collected from participants, they experienced that HIV disclosure helped them in terms of support in the workplace. However, some had emotionally experienced stigmatisation and a fear of rejection and death. It was clear that due to physical and emotional challenges, the participants found themselves compelled to disclose their HIV status in the workplace. From the data collected, it was evident that HIV status disclosure in the workplace has both negative and positive consequences, therefore it was crucial for an individual to work through his/her emotional feelings and decide whether to disclose or not.

The next chapter presents the overview of the goal and objectives of the study, how these objectives have been achieved and, based on the findings, the conclusions are set out and recommendations are formulated with regard to the experiences of employees in the transport sector after they have disclosed their HIV status in the workplace. These recommendations can be used as guidelines in developing strategies for dealing with HIV status disclosure in the workplace.

## CHAPTER FOUR

### CONCLUSIONS AND RECOMMENDATIONS

#### 4.1 Introduction

To be diagnosed with HIV is a life-threatening and a life changing situation. An individual has to learn to cope with the emotional and physical challenges associated with being HIV positive. There is no doubt that HIV has also a huge financial impact on an organisation. It is therefore critical for organisations to mitigate the impact of HIV and AIDS and to provide support to those employees who have tested HIV positive for them to live a productive life. Therefore, disclosure of a person's HIV status becomes an important, although a very sensitive, issue in the field of HIV. Over and above this, every individual has a right to privacy and dignity, including HIV status in the workplace. In order to understand HIV infected employees' experiences after disclosure of their HIV statuses, the researcher formulated the following research goal: **to explore the experiences of HIV positive employees in the transport sector after they have disclosed their status in the workplace.**

In order to attain the goal of the study the following objectives were formulated:

- to theoretically conceptualise HIV as a phenomenon with specific emphasis on disclosure in the workplace;
- to explore the experiences of HIV positive employees in the transport sector after they have disclosed their HIV status in the workplace; and
- to draw conclusions based on the research findings and formulate recommendations to address HIV disclosure problems in the workplace.

Against this background the following research question guided the study:

**What are the experiences of HIV positive transport sector employees after they have disclosed their HIV status in the workplace?**

In this final chapter, based on the findings, the researcher will present conclusions as well as recommendations concerning the experiences of HIV status disclosure in the workplace and also further research.

## 4.2 Conclusions

Based on the empirical findings the following conclusions with regards to employees' experiences of HIV status disclosure in the workplace can be made:

- **Support systems:**

Although the majority of participants credited the workplace for support, they also highlighted the Employee Wellness Practitioners as their great support system in the workplace. However, a few participants experienced lack of support after they had disclosed, particularly from their managers, and they in fact experienced humiliation and high levels of stress. They attributed the lack of support from managers to low levels of HIV knowledge.

- **Stigma**

It was therefore established that, despite the huge progress in managing HIV and AIDS in the workplace by providing workplace programmes and policies, stigma and lack of knowledge still pose a challenge for People Living with HIV/AIDS in the workplace resulting in some emotional challenges.

- **Level of HIV knowledge in the workplace.**

It seems as if lack of HIV knowledge contributes to high stigma levels that exist in the workplace as far as HIV is concerned.



- **Reasons for disclosure of HIV status**

Although a majority of participants have voluntarily disclosed their HIV status in the workplace, ill health, poor performance and absenteeism were identified as the most compelling reasons for disclosure in the workplace.

- **Benefits of disclosure:**

HIV status disclosure in the workplace was described as beneficial accessing social and medical support in the workplace and at a personal level as there was no need to live with the secrecy anymore. Thus another important finding experienced by participants was that of a sense of relief and lightness after they have disclosed their HIV status in the workplace.

- **Emotional reactions**

The empirical findings confirmed that HIV is a multi-dimensional phenomenon with both physical and psychosocial challenges. It was also evident from the findings that employees who had disclosed their HIV status in the workplace had a full range of varying experiences ranging from anger and blame, to fear of rejection and imminent death. HIV status disclosure was a process that required an individual to be ready before a decision to disclose was made. Thus a need for therapeutic intervention is important.

- **Challenges of being on ARV.**

Although taking ARVs has been proven to prolong life and keep employees as productive as they possible can, it seems that being on ARVs in the workplace has a number of challenges. These challenges may contribute to high absenteeism rates in the workplace due to physical challenges and lack of privacy associated with taking ARVs.

### **4.3 Recommendations**

Based on the empirical findings, the following recommendations can be made.

#### **4.3.1 *Recommendations with regard to HIV and AIDS policy***

- Workplace HIV and AIDS policies should be developed according to the National HIV and AIDS policy framework and guidelines. Any policy should be a living document, particularly the HIV and AIDS policy, as it is evident from the findings that employees experience workplace support and knowledge on HIV and AIDS issues differently.
- In the context of the transport sector, policies should be customised according to the different needs of the various agencies of the transport sector. Thus greater involvement of employees who are living with HIV in policy drafting should be mandatory. Policy review should be based on the results of the Knowledge, Attitudes, Behaviour and Perception (KABP) of the different transport sector agencies; this would ensure that HIV policies are addressing specific issues in that workplace. Furthermore, KABP should be conducted bi-annually to measure the impact of HIV and AIDS awareness strategies.

#### **4.3.2 *Recommendations with regard to HIV and AIDS knowledge capacity building programme for managers and supervisors.***

To enhance HIV knowledge, capacity building programmes for managers should include aspects of managing HIV disclosure in the workplace.

#### **4.3.3 *Recommendations with regard to integrating HIV and AIDS management in the workplace to management Key Performance Indicators (KPI)***

- As per the findings, HIV and AIDS have a great impact on absenteeism and performance. Therefore the aspect of HIV management should form part of management key performance indicators. This will ensure that everybody

participates in HIV related activities and takes responsibility to implement the employer's HIV and AIDS initiatives, thus encouraging disclosure.

- As management has a responsibility to implement company policies and guidelines to protect the employer from litigation and legal implications, it should be managements' responsibility to provide the necessary support system and thus improve productivity, and also reduce the costs associated with HIV and AIDS in the transport sector.

#### ***4.3.4 Recommendations with regard to support***

It is crucial for the transport sector to establish workplace support groups at all levels as it is clear from the empirical findings that all occupational levels are affected by HIV. Establishment of support groups will minimise stigma and encourage behavioural change and HIV status disclosure in the workplace. HIV and AIDS should form part of the agenda at a strategic level and the government should impose penalties for non-compliance.

#### ***4.3.5 Recommendations with regard to therapeutic programmes***

There is no doubt that companies will see a large return on investment from establishing an integrated Employee Assistance Programme and HIV and AIDS workplace programmes to mitigate the impact of absenteeism and enhance productivity. As it was evident that HIV and AIDS is a multidimensional phenomenon, it is recommended for workplaces to develop therapeutic programmes as these will benefit the workplace in dealing with the psycho-social impact of HIV and preparing the individual towards disclosure of HIV status.

#### ***4.3.6 Recommendations with regard to further research***

More research still needs to be conducted at the following actions should be taken.

- Since managers are the first point of contact in the value chain, research should be done to investigate experiences of managers as the targeted group for disclosure of HIV status by employees in the workplace.
- Empirically investigate the support given by managers to employees who have disclosed their HIV status.
- Assess the extent of HIV stigmatisation in the workplace after HIV status disclosure.
- Evaluate the effectiveness of the implementation of the HIV and AIDS policies in the workplace.
- Explore the role of employee diversity in the workplace with regards to mitigating the impact of HIV.

#### **4.4 Achievement of the goal and objectives of the study.**

The goal of the study has been to explore the experiences of HIV positive employees in the transport sector after they have disclosed their HIV status in the workplace.

Table 4.1 focuses on how the goal and objectives of the study were achieved.

**Table 4.1 Summary of the achievement of objectives**

Nr	Objective	Objective achieved
1	To theoretically conceptualise HIV as a phenomenon with specific emphasis on HIV disclosure in the workplace.	This objective was achieved as per discussion presented in Chapter Two.
2	To explore the experiences of HIV positive employees in the transport sector after they have disclosed their HIV status in the workplace.	This objective was achieved through the discussion in Chapter Three based on the qualitative empirical findings on the experiences of HIV positive employees in the transport sector after they have disclosed their HIV status in the workplace.
3	To draw conclusions and make recommendations based on the findings to address problems with HIV status disclosure in the workplace.	The objective was achieved through the discussions and recommendations in Chapter Four.

#### **4.5 Summary**

The aim of this study was to explore the experiences of employees in the transport sector who tested HIV positive and have disclosed their status in the workplace. The experiences of being HIV positive in the workplace and the challenges of living with the disease were discussed. It has been noted in this study that HIV status disclosure was only partial as participants disclosed to certain individuals rather than an inclusive disclosure where an individual would disclose to the entire workplace.

This study has revealed that employees who are HIV positive and have disclosed their status in the workplace face different challenges. These challenges include but are not limited to: stigmatisation, fear, and both psychological and physical challenges which may result in poor work performance and a high rate of absenteeism. These challenges have been associated with low level of knowledge of HIV related issues.

However, the study also revealed the availability of support systems in the workplace and that HIV status disclosure in the workplace had some advantages. One of the major advantages of the disclosure in this study was that the disclosure was voluntary, therefore individuals were able to manage their disclosure. The workplace can have a considerable impact in mitigating the scourge of HIV in the workplace and thus should encourage disclosure. The study has been concluded by recommending a program of action based on the empirical findings and recommendations for future research.

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## ANNEXURE A

### INFORMED CONSENT FORM

Participant's Name: \_\_\_\_\_

Date: \_\_\_\_\_

Principal Researcher:

Name: \_\_\_\_\_

Institution: \_\_\_\_\_

Address: \_\_\_\_\_

\_\_\_\_\_

#### Informed Consent

1. Title of Study: The experiences of transport sector employees after their disclosure of living with HIV.
2. Purpose of the Study: The purpose of this study is to explore the experiences of people living with HIV/AIDS in the workplace after they have disclosed their HIV status.
3. Procedures: The interview will take approximately one to two hours. All interviews will be scheduled at the participant's convenience.

4. Risks and Discomforts: There are no known medical risks or discomforts associated with this project, although I may experience some emotional discomfort due to the fact that I will be asked questions relating to my personal life. I have been informed of the debriefing session that will be conducted after the data collection session and believe that this will help me deal with my emotions emanating from this study.
5. Benefits: I understand that there are no direct personal benefits for me for participating in this study. However, the results of the study may help researchers gain a better understanding of how our experiences may contribute to the development of certain programmes that will deal with disclosure of HIV/AIDS in the workplace.
6. Participant's Rights: I am aware of the fact that I may withdraw from participating in the study at any time, should I find it unbearable to continue.
7. Financial Compensation: There is no financial gain related to my participation in this project.
8. Confidentiality: In order to record exactly what I say in the interview, a tape recorder will be used. The tape will be listened to only by the Principal Researcher and authorised members of the research team to ensure confidentiality of the information.
9. I understand that the information that I am going to share with the researcher will be kept confidential. The results of this study may be published in professional journals or presented at professional conferences.
10. If I have any questions or concerns, I can call Linda Peter (0845811232) at any time during the day or night.

I understand my rights as a participant and I voluntarily consent to participating in this study. I understand what the study is about and how and why it is being done. I will receive a signed copy of this consent form.

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Participant's Signature

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DATE

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Signature of Researcher

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DATE

---

Signature of the Supervisor

---

DATE



